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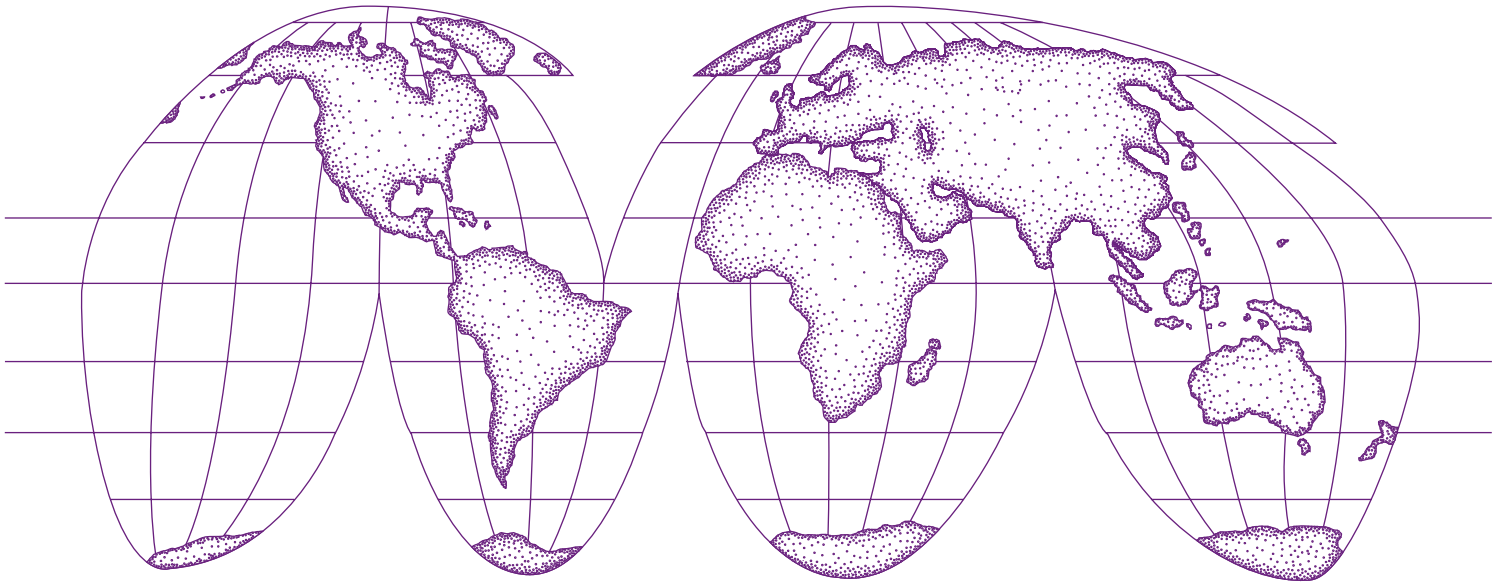
Proceedings of the International Collaborative Effort on Automating Mortality Statistics, Volume III



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
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National Center for Health Statistics

Edward J. Sondik, Ph.D., *Director*

Jennifer H. Madans, Ph.D., *Acting Co-Deputy Director*

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Margot A. Palmer, *Acting Director for Information Services*

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Division of Vital Statistics

Charles J. Rothwell, *Director*

James A. Weed, Ph.D., *Deputy Director*

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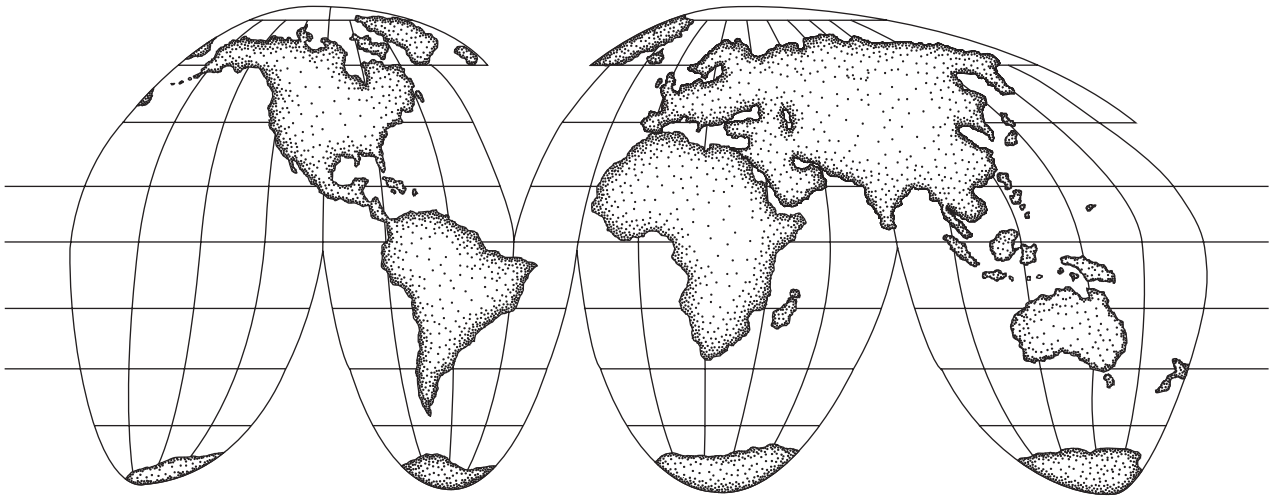
Arialdi M. Minino and Harry M. Rosenberg, Editors



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention
National Center for Health Statistics

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Preface

This volume contains presentations delivered at the third plenary meeting of the International Collaborative Effort (ICE) on Automating Mortality Statistics held April 7–10, 2003 in Washington, DC. The mission of the ICE on Automation is to (1) share knowledge and experience of automated systems for coding mortality information, (2) develop and improve existing automated systems through international collaboration, (3) facilitate the transition to ICD–10 for mortality, and (4) establish mechanisms for technical support of automated systems. At the third ICE plenary, over 80 participants from 25 countries came together to discuss these issues.

The third ICE plenary meeting recognized the continuing, and largely successful, efforts to implement the recommendations of the first ICE meeting. These recommendations led to the establishment of the Mortality Forum, the WHO Mortality Reference Group, the WHO Electronic Tools Committee, the WHO Subgroup on Education, and the NCHS international training program on mortality coding for automated systems, all in the years following the first ICE plenary. These groups are now firmly established in the international sphere and follow a regular routine of meetings and other activities.

The third plenary meeting also saw the introduction of several themes that will remain the focus of the ICE on Automation in future years: growing international collaboration on the development of automated coding systems; the widespread and growing interest in electronic registration of deaths and certification of cause of death; and efforts to simplify the adaptation of automated coding systems for use in different languages. The conference included presentations on a variety of topics related to automating mortality statistics, including comparability studies, automation and coder training, electronic death registration, language issues in automated systems, analysis of multiple causes of death, and knowledge and data dissemination. In addition, a panel discussion on data quality used an innovative question-and-answer format to provide expert answers and discussion of issues raised by the conference participants.

We remain very pleased with the interest and collaboration generated by this ICE, and look forward to continuing this activity into the future.

The editors:
Harry M. Rosenberg
Melonie Heron
Arialdi M. Miniño

National Center for Health Statistics

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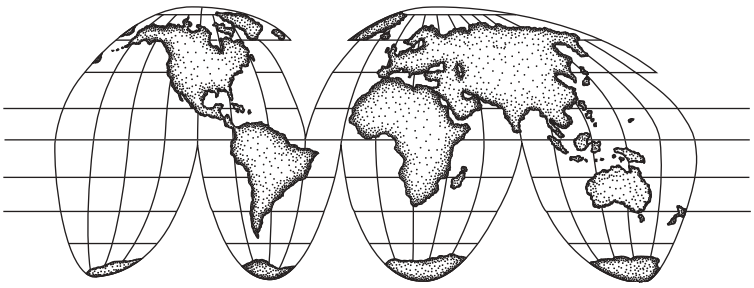
This conference of the International Collaborative Effort on Automating Mortality Statistics was sponsored by the Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS). The Open Society Institute and the World Bank provided travel support for meeting participants from Central and Eastern Europe and the newly independent states. Coordination of international travel arrangements and hotel facilities was managed by Courtesy Associates and staff from NCHS's Office of International Statistics, Mortality Statistics Branch, and Office of Management and Operations. Pat Drummond, Administrative Operations, Office of Management and Operations, NCHS, managed meeting registration and served as hotel facilities coordinator.

Much credit for the success of the conference is due to Sam Notzon, of the Office of International Statistics, who served as principal coordinator of the event and chaired the conference in general.

Finally, the editors wish to thank the presenters, authors, and participants for their contributions to this volume. The editors for this volume were Harry M. Rosenberg (retired), formerly of the Mortality Statistics Branch (MSB), Melonie Heron, and Arialdi Miniño, also of NCHS's MSB. The publication manager was Demarius V. Miller of the Office of Information Services, Information Design and Publishing Staff, NCHS, and typesetting done by Jacqueline M. Davis of CoCHIS/NCHM/Division of Creative Services. Comments concerning individual presentations should be directed to the particular authors or presenters whose addresses are included in the following pages.

Participants



Participants of the International Collaborative Efforts on Automating Mortality Statistics

- **Row 1 Left to Right:** Tanya Pitts, Joyce Bius, Liuda Kasparaviciene, Suzanne Marsh, Angela Hinds, Asunción Piñán Gaviria, Carmen Salaices Sánchez, Arialdi Miniño, Sam Notzon, Harry Rosenberg, Moriyo Kimura, Ene Palo, Morten Hjulsager, Laila Christensen, Ed Elliot, Francesca Coullare.
- **Row 2 Left to Right:** Patricia Wood, Marjorie Greenberg, David Lidsky, Augusto Hasiak Santo, Monika Bene, Cassia M. Buchalla, John Silvi, Finn Gjertsen, Ruy Laurenti, Karen Horne, Leslie Geran, Sue Walker, Monica Pace, Tsung-Hsue Lu, Julia Raynor, Kirsten Møller-Hansen, Jožica Šelb Šemerl, Karlsone Sniedze, Tyringa Ambrose.
- **Row 3 Left to Right:** Juan Antonio Ortega García, Steven Schwartz, Eric Stallard, Ron Casey, Roberto Becker, Bedirhan Ustun, Kenneth D. Kochanek, James Weed, Robert Anderson, Henry Walke, Bassam Jarrar, Graham Jackson, Thomas Bartvig, Henrik Mulvad Hensen.
- **Row 4 Left to Right:** Tim Walker, Lars Age Johansson, Donna Glenn, Christiane Rosenow, George Legall, Jaume Canela-Soler, David Vaisman, Michael Schopen, Gérard Pavillon, John Menic, Eric Jougla, Cleo Rooney, Kim Bu-Yeon, Lois Cook, Michael Coglan, Jae-won Lee, Stefano Marchetti, Antonio Escobedo
- **Not in picture:** Greg Adas, Juan Albertorio, Sulaiman Bah, Grace Bediako, David Berglund, Patricia Drummond, Yelena Gorina, Donna Hoyert, Donna Pickett, Nina Schwalbe, Ed Sondik, Bill Steiger.

Participants
April 7–10, 2003

Juan R. Albertorio-Diaz
Statistician
Office of International Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention
3311 Toledo Road, Room 2427
Hyattsville, Maryland 20782
USA
Tel: 301 458 4634
Fax: 301 458 4043
E-mail: JAlbertorio@cdc.gov

Greg Adas
Technical Training Developer
Analytical Sciences, Inc.
National Center for Health Statistics
Centers for Disease Control and Prevention
P.O. Box 12214
Research Triangle Park, NC 27709
USA
Tel: 919 541 2305
Fax:
Email: GAdas@Sciences.com

Tyringa Ambrose
Mortality Medical Classification Branch
Division of Vital Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention
4105 Hopson Road
Research Triangle Park, NC 27709
USA
Tel: 919 541 3981
Fax: 919 541 5211
E-mail: TLA1@cdc.gov

Robert Anderson
Lead Statistician
Mortality Statistics Branch
Division of Vital Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention
3311 Toledo Road, Room 7318
Hyattsville, Maryland 20782
USA
Tel: 301 458 4073
Fax: 301 458 4034
E-mail: RNAnderson@cdc.gov

Beverly Andrews
Biostatistician
Caribbean Epidemiology Centre (CAREC)
16–18 Jamaica Boulevard
Federation Park
REPUBLIC OF TRINIDAD AND TOBAGO
Tel: 868 622 4261
Fax: 868 622 1008
E-mail: AndrewBe@carec.paho.org

Sulaiman M. Bah
Deputy Director, Vital Statistics, Population
Projections, Tourism and Migration
Statistics South Africa
Steyn's Arcade
274 Schoeman Street
Private Bag X44
0001 Pretoria
SOUTH AFRICA
Tel: 2712 310 8678
Fax: 2712 310 6937
E-mail: SulaimanBstatssa.gov.za

Thomas Bartvig
Danish National Board of Health
Islands Brygge 67
DK-2300 Copenhagen S
DENMARK
Tel: 45 7222 7718
Fax: 45 7222 7411
E-mail: thbsst.dk

Roberto Becker
Regional Advisor on ICD
Pan American Health Organization
525 23rd Street, NW
Washington, D.C. 20037–2895
USA
Tel: 202 974 3131
Fax: 202 974 3674
E-mail: BeckerRopaho.org

Grace Bediako
Chief, Demographic Section
United Nations Statistics Division
2, UN Plaza DC2–1556
New York, New York 10017
USA
Tel: 212 963 7771
Fax: 212 963 1940
E-mail: Bediakoun.org

Mónika Bene
Central Statistical Office of Hungary
Központi Statisztikai Hivatal
Keleti Károly u. 5–7
1024 Budapest
HUNGARY
Tel: 36 1 345 6685
Fax: 36 1 345 6678
E-mail: Monika.Beneoffice.ksh.hu

David Berglund
Medical Officer
National Center for Health Statistics
Centers for Disease Control and Prevention
3311 Toledo Road, Room 2415
Hyattsville, Maryland 20782
USA
Tel: 301 458 4095
Fax: 301 458 4022
E-mail: DBerglund@cdc].gov

Joyce L. Bius
Medical Classification Specialist
Mortality Medical Classification Branch
Division of Vital Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention
4105 Hopson Road
Research Triangle Park, NC 27709
USA
Tel: 919 541 3119
Fax: 919 541 5211
E-mail: JBius@cdc].gov

Cassia Maria Buchalla
Assessor, WHO Collaborating Centre for
the Classification of Diseases in
Portuguese
School of Public Health
University of Sào Paulo
Av. Dr. Arnaldo 715-room 40
CEP 01246–904 Sào Paulo-SP
BRAZIL
Tel: 55 11 3066 7747
Fax: 55 11 883 4246
E-mail: CMBuchalusp.br

Kim Bu-Yeon
Nosologist, Mortality Statistics Section
National Statistical Office
Government Complex
920, Dunsan-dong, Seo-gu
Daejeon 302–701
REPUBLIC OF KOREA
Tel: 82 42 481 2260
Fax: 82 42 481 2470
E-mail: KBYnso.go.kr

Jaume Canela-Soler
Regional Adviser of Biostatistics
AIS/PAHO
525 23rd Street, N.W.
Office 611
Washington, DC 20037
USA
Tel: 202 974 3484
Fax: 202 974 3674
Email: Canelajapaho.org

Ron Casey
Director
Population and Social Statistics
Australian Bureau of Statistics
GPO Box 9817
Brisbane Qld 4001
AUSTRALIA
Tel: 61 7 3222 6312
Fax: 61 7 3222 6038
E-mail: Ron.Casey@abs.gov.au

Laila Christensen
Head of Section
The Danish National Board of Health
Sundhedsstyrelsen
Islands Brygge 67
DK 2300 Copenhagen
DENMARK
Tel: 45 72 22 7603
Fax: 45 72 22 7415
E-mail: LaCsst.dk

Michael Coghlan
Manager, Registration Services
NSW Registry of Births, Deaths and Marriages
Box 30 GPO
Sydney NSW 2001
AUSTRALIA
Tel: 61 2 8306 8487
Fax: 61 2 9699 5319
E-mail: MCoghlan@agd.nsw.gov.au

Lois Cook
Branch Head, Mortality Statistics
Office for National Statistics (ONS)
Room B6/04
1 Drummond Gate
London SWIV 2QQ, England
UNITED KINGDOM
Tel: 44 207 533 5245
Fax: 44 207 533 5635
E-mail: Lois.Cookons.gov.uk

Francesca Coullare
Statistician
United Nations Statistics Division
2, UN Plaza DC2–1534
New York, New York 10017
USA
Tel: 212 963 4950
Fax: 212 963 1940
E-mail: Coullareun.org

Patricia Drummond
National Center for Health Statistics
Centers for Disease Control and Prevention
3311 Toledo Road, Room 1310
Hyattsville, Maryland 20782
USA
Tel: 301 458 4193
Fax: 301 458 4022
E-mail: Pdrummond@cdc.gov

Edward K. Elliot
Principal Software Developer
Analytical Sciences, Inc.
National Center for Health Statistics
Centers for Disease Control and Prevention
P.O. Box 12214
Research Triangle Park, NC 27709
USA
Tel: 919 541 0068
Fax: 919 541 4098
E-mail: EElliot@cdc.gov

Antonio Escobedo-Aguirre
Director of Demographic and Social Statistics
National Institute of Statistics, INEGI
Av. Héroe de Nacozari Sur 2301
Puerta 11 Nivel 2 (DEDS)
Fracc. Jardines del Parque
CP 20270
Aguascalientes
MEXICO
Tel: 52 449 918 3336
Fax: 52 449 918 2418
E-mail: AEscobed@dge.inegi.gob.mx

Asunción Piñán Gaviria
Jefe De Area Sistemas Generales
National Statistical Institute of Spain
Calle Josefa Valcarcel No. 46
28027 Madrid
SPAIN
Tel: 34 915 837 757
Fax: 34 915 838 796
E-mail: APinanine.es

Leslie Geran
Senior Analyst
Health Statistics Division
Statistics Canada
R.H. Coats Building, 18th Floor
Tunney's Pasture
Ottawa, KIA OT6 Ontario
CANADA
Tel: 613 951 5243
Fax: 613 951 0792
E-mail: Leslie.Geranstatcan.ca

Finn Gjertsen
Norwegian Institute of Public Health
http://www.fhi.no
Tel: +47-23 40 82 32
Mailaddress: P.O. Box 4404 Nydalen, 0403 NO-Oslo
E-mail: finn.gjertsen@fhi.no

Donna E. Glenn
Chief, Mortality Medical Classification Branch
Division of Vital Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention
P.O. Box 12214
Research Triangle Park, NC 27709
USA
Tel: 919 541 0999
Fax: 919 541 2471
E-mail: DEGlenn@cdc.gov

Yelena Gorina
National Center for Health Statistics
Centers for Disease Control and Prevention
3311 Toledo Road, Room 6331
Hyattsville, Maryland 20782
USA
Tel: 301 458 4241
Fax: 301 458 4037
E-mail: YGorina@cdc.gov

Marjorie Greenberg
Chief, Classifications and Public Health
Data Standards
National Center for Health Statistics
Centers for Disease Control and Prevention
3311 Toledo Road, Room 2413
Hyattsville, Maryland 20782
USA
Tel: 301 458 4245
Fax: 301 458 4022
E-mail: MGreenberg@cdc.gov

Henrik Mulvad Hensen
Project Manager
The Danish National Board of Health
Islands Brygge 62
Postboks 1881
DK 2300 Copenhagen
DENMARK
Tel: 45 72 22 7400
Fax: 45 72 22 7415
E-mail: HMHsst.dk

Angela Hinds
Computer Systems Analyst
Caribbean Epidemiology Centre (CAREC)
6–18 Jamaica Boulevard
Federation Park
REPUBLIC OF TRINIDAD AND TOBAGO
Tel: 868 622 4261
Fax: 868 622 1008
E-mail: HindsAng@carec.paho.org

Karen Horne
Consultant
Canadian Institute for Health Information
90 Eglinton A venue East
Suite 300
Toronto, M4P 2Y3 Ontario
CANADA
Tel: 416 481 2002 ext. 3564
Fax: 416 481 2950
E-mail: KHorne@cihi.ca

Morten Hjulsager
Head, Division of Health Statistics
Danish National Board of Health
Islands Brygge 67
Postboks 1881
2300 København S
DENMARK
Tel: 45 7222 7826
Fax: 45 7222 7404
E-mail: mhjsst.dk

Donna Hoyert
Statistician
Mortality Statistics Branch
Division of Vital Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention
3311 Toledo Road, Room 7318
Hyattsville, Maryland 20782
USA
Tel: 301 458 4279
Fax: 301 458 4034
E-mail: DHoyert@cdc.gov

Graham Jackson
Head of Vital Events and NHS Branch
General Register Office for Scotland
Ladywell House, Ladywell Road
Edinburgh EH12 7TF, Scotland
UNITED KINGDOM
Tel: 44 131 314 4229
Fax: 44 131 314 4682
E-mail: Graham.Jacksongro-scotland.gov.uk

Bassam Jarrar
Public Health Advisor
Epidemiology Program Office
Centers for Disease Control and Prevention
4770 Buford Highway
MS K72
Atlanta, Georgia 30341
USA
Tel: 770 488 8330
Fax: 770 488 8455
E-mail: Bjarrar@cdc.gov

Lars Age Johansson
Senior Executive Officer
Statistics Sweden
Statistics Programme for Health and
Social Welfare
P.O. Box 24300, S-104 51 Stockholm
SWEDEN
Tel: 46 8 783 4498 or 46 8 82 6314
Fax: 46 8 783 4652 or 46 8 82 6314
E-mail: Lars.Age.Johanssonsos.se

Eric Jougla
SC8-INSERM
44, Chemin de Ronde
78116 Le Vésinet Cedex
FRANCE
Tel: 33 1 34 80 24 33
Fax: 33 1 34 80 24 29
E-mail: Jouglavesinet.inserm.fr

Sniedze Karlsone
Chief, Demographic Unit
Health Statistics Department
Health Statistics and Medical Technology Agency
Duntes Street 12/22
Riga, LV-1005
LATVIA
Tel: 371 750 1594
Fax: 371 750 1591
E-mail: demografijavsmta.lv

Liuda Kasparaviciene
Chief Specialist
Demographic Statistics Division
Statistics Lithuania
Gedimino Ave. 29
Vilnius
LITHUANIA
Tel:
Fax: 370 5 236 49 45
E-mail: LiudaKmail.std.lt

Moriyo Kimura
Director, Office of ICD
Statistics and Information Department
Ministry of Health, Labour and Welfare
1–2-2 Kasumigaseki
Chiyoda-ku, 100–8916
Tokyo
JAPAN
Tel: 81 3 5253 1111
Fax: 81 3 3595 1670
E-mail: Kimura-Moriyomhlw.go.jp

Kenneth Kochanek
Statistician
Mortality Statistics Branch
Division of Vital Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention
3311 Toledo Road, Room 7318
Hyattsville, Maryland 20782
USA
Tel: 301 458 4319
Fax: 301 458 4034
E-mail: KDK2@cdc].gov

Ruy Laurenti
Head, WHO Collaborating Centre for the Classification of Diseases in Portuguese
School of Public Health
University of São Paulo
Av. Arnaldo, 715
CEP 01246–904 São Paulo SP
BRAZIL
Tel: 55 11 883 4246/55 11 3066 7747
Fax: 55 11 883 4246
E-mail: Laurentiusp.br

George Legall
Biostatistician
Caribbean Epidemiology Centre (CAREC)
16–18 Jamaica Boulevard
Federation Park
REPUBLIC OF TRINIDAD AND TOBAGO
Tel:
Fax:
E-mail: legallge@carec.paho.org

Jae-won Lee
Chief, Mortality Statistics Section
National Statistical Office
Government Complex
920, Dunsan-dong, Seo-gu
Daejeon 302–701
REPUBLIC OF KOREA
Tel: 82 42 481 2261
Fax: 82 42 481 2470
E-mail: JWLeenso.go.kr

David Lidsky
Coder
Israel Central Bureau of Statistics
66 Kanfei Nesharim St.
Jerusalem, 95464
ISRAEL
Tel: 972 2 6592550
Fax: 972 2 6592503
E-mail: DLidsky@cbs.gov.il

Tsung-Hsueh Lu
Department of Family Medicine
Chung Shan Medical University
110, Section 1, Chien Kuo North Road
Taichung 402
TAIWAN
Tel: 886 4 24739595 ext. 4719
Fax: 886 4 22295768
E-mail: RobertLums1.hinet.net

Stefano Marchetti
ISTAT
Dipartimento Delle Statistiche Sociali
Viale Miegi, I3
00198 Rome
ITALY
Tel: 0039 06 8522 7396
Fax: 0039 06 8522 7601
E-mail: StMarcheistat.it

Suzanne Marsh
Statistician
NIOSH
1095 Willowdale Road, MS 1808
Morgantown, West Virginia 26505
USA
Tel: 304 285 6009
Fax: 304 285 5774
E-mail: SMM2@cdc.gov

John Menic
Health Statistics Division
Statistics Canada
R.H. Coats Building, 18th Floor
Tunney's Pasture
Ottawa, KIA OT6 Ontario
CANADA
Tel: 613 951 1654
Fax:
E-mail: John.Menicstatcan.ca

Arialdi Miniño
Statistician
Mortality Statistics Branch
Division of Vital Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention
3311 Toledo Road, Room 7318
Hyattsville, Maryland 20782
USA
Tel: 301 458 4376
Fax: 301 458 4034
E-mail: AMinino@cdc.gov

Kirsten Møller-Hansen
Medical Officer
The Danish National Board of Health
Islands Brygge 67
Postboks 1881
DK 2300 Copenhagen
DENMARK
Tel: 45 72 22 7601
Fax: 45 72 22 7415
E-mail: KMHsst.dk

Sam Notzon
Special Assistant for Global Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention
3311 Toledo Road, Room 2425
Hyattsville, Maryland 20782
USA
Tel: 301 458 4402
Fax: 301 458 4043
E-mail: SNotzon@cdc.gov

Juan-Antonio Ortega-Garcia
National Institute of Statistics, INEGI
Av. Héroe de Nacozari Sur 2301
Puerta 11 Nivel 2 (DEDS)
Fracc. Jardines del Parque
CP 20270
Aguascalientes
MEXICO
Tel: 52 449 910 5418
Fax: 52 449 918 2418
E-mail: apoyoest@dge.inegi.gob.mx

Monica Pace
ISTAT
Dipartimento Delle Statistiche Sociali
Viale Miegi, I3
00198 Rome
ITALY
Tel: 39 06 85227394
Fax:
E-mail: MoPaceistat.it

Ene Palo
Medical Statistics Bureau
Ministry of Social Affairs of Estonia
15 Endla Street
EE-0100 Tallin
ESTONIA
Tel:
Fax: 372 2 45 39 23
E-mail: Ene.Palosm.ee

Gérard Pavillon
Head, Centre Collaborateur OMS pour la
Classification Internationale des Maladies
En Langue Française
SC8-INSERM
44, Chemin de Ronde
78116 Le Vésinet Cedex
FRANCE
Tel: 33 1 34 80 24 62
Fax: 33 1 34 80 24 29
E-mail: Pavillonvesinet.inserm.fr

Donna Pickett
Medical Systems Administrator
National Center for Health Statistics
Centers for Disease Control and Prevention
3311 Toledo Road, Room 2337
Hyattsville, Maryland 20782
USA
Tel: 301 458 4434
Fax: 301 458 4022
E-mail: DPickett@cdc.gov

Tanya W. Pitts
Medical Classification Specialist
Mortality Medical Classification Branch
Division of Vital Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention
4105 Hopson Road
Research Triangle Park, NC 27709
USA
Tel: 919 541 7872
Fax: 919 541 5211
E-mail: TPitts@cdc.gov

Julia E. Raynor
Medical Classification Specialist
Mortality Medical Classification Branch
Division of Vital Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention
4105 Hopson Road
Research Triangle Park, NC 27709
USA
Tel: 919 541 4408
Fax: 919 541 5211
E-mail: JRaynor@cdc.gov

Cleone Rooney
Medical Epidemiologist
Office for National Statistics (ONS)
SESAG/D&H
RoomB7/04
1 Drummond Gate
London SW1 V 2QQ, England
UNITED KINGDOM
Tel: 44 207 533 5254
Fax: 44 207 533 5103
E-mail: Cleo.Rooneyons.gov.uk

Harry M. Rosenberg
(Retired) Formerly, Chief, Mortality
Statistics Branch
Division of Vital Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention
7008 Richard Drive
Bethesda, Maryland 20817
USA
Tel: 301 229 4406
Fax:
E-mail: HarryMRosenberg@aol.com

Christiane Rosenow
Federal Statistical Office of Germany
Statistisches Bundesamt
Zweigstelle Bonn, Abteilung VIII
Graurheindorfer Str. 198
53117 Bonn
GERMANY
Tel: 49 1888 6448 108
Fax: 491888 6448 996
E-mail: Christiane.Rosenow@destatis.de

Carmen Salaices Sanchez
Jefe Del Area Estadisticas Vitales
National Statistical Institute of Spain
Paseo de la Castellana No. 183
28070 Madrid
SPAIN
Tel: 34 915 839 195
Fax: 34 915 839 106
E-mail: Salaicesine.es

Augusto Hasiak Santo
Faculdade de Saude Publica
Universidade de São Paulo
Av. Dr Arnalda 715
São Paulo 01246–904
BRAZIL
Tel: 55 11 883 5738
Fax: 55 11 883 2108
E-mail: AuhSantousp.br

Michael Schopen
Deutsches Institut für Medizinische Dokumentation
und Information (DIMDI)
Waisenhausgasse 36–38A
D-50676 Cologne
GERMANY
Tel: 49 221 4724 325
Fax: 49 221 4724 444
E-mail: Scholpen@dimdi.de

Nina Schwalbe
Director, Open Society Institute
Network Public Health Program
400 West 59th Street, 4th Floor
New York, New York 10019
USA
Tel: 212 548 0324
Fax: 212 548 4610
E-mail: NSchwalbesorosny.org

Steven Schwartz
Registrar and Assistant Commissioner
Office of Vital Statistics
New York City Department of Health and
Mental Hygiene
125 Worth Street, Box 7
New York, New York 10013
USA
Tel: 212 788 4575
Fax: 212 788 4580
E-mail: SSchwarthealth.nyc.gov

Jožica Šelb Šemerl
Head, Mortality Statistics Department
Institute of Public Health of the
Republic of Slovenia
Trubarjeva cesta 2
1000 Ljubljana
SLOVENIA
Tel: 386 1 2441 460
Fax: 386 1 2441 530
Email: Jozica.SelbIVZ-RS.SI

John Silvi
Research Information Specialist
AIS/PAHO
525 23rd Street, N.W.
Office 610
Washington, DC 20037
USA
Tel: 202 974 3141
Fax: 202 974 3674
Email: Silvijhnpaho.org

Karlsone Sniedze
Chief, Demographic Unit
Health Statistics Department
Health Statistics and Medical Technology
Agency
Duntes Street 12/22
Riga, LV-1005
LATVIA
Tel: 371 7501594
Fax: 371 7501591
E-mail: demografijavsmta.lv

Edward Sondik
Director
National Center for Health Statistics
Centers for Disease Control and Prevention
3311 Toledo Road, Room 7209
Hyattsville, Maryland 20782
USA
Tel: 301 458 4500
Fax:
E-mail: ESondik@cdc.gov

Eric Stallard
Research Professor of Demographic Studies
and Associate Director, Center for
Demographic Studies
Duke University
2117 Campus Drive, Box 90408
Durham, North Carolina 27708–0408
USA
Tel:
Fax:
E-mail: Eric@cds.duke.edu

Bedirhan Ustun
Global Programme on Evidence for
Health Policy
World Health Organization
Avenue Appia 20
CH-1211, Geneva 27
SWITZERLAND
Tel: 41 22 791 2418
Fax: 41 22 791 4894
E-mail: UstunBwho.int

David Vaisman
Bureau for Medical Statistics
114, Oboronnaja Street
Tula, Tula oblast, 300045
RUSSIAN FEDERATION
Tel: 7 0872 373 388
Fax:
E-mail: David@admin.phtula.mednet.com

Sue Walker
Associate Director
National Centre for Classification in Health
Queensland University of Technology
School of Public Health
Victoria Park Road
Kelvin Grove 4059
Queensland
AUSTRALIA
Tel: 61 7 3864 5873
Fax: 61 7 3864 5515
E-mail: S.Walkerqut.edu.au

Tim Walker
Scientific Technical Manager
Analytical Sciences, Inc.
National Center for Health Statistics
Centers for Disease Control and Prevention
P.O. Box 12214
Research Triangle Park, NC 27709
USA
Tel: 919 541 0101
Fax:
E-mail: TWalker@asciences.com

James Weed
Acting Director
Division of Vital Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention
3311 Toledo Road, Room 7318
Hyattsville, Maryland 20782
USA
Tel: 301 458 4561
Fax: 301 458 4034
Email: Jweed@cdc.gov

Patricia Wood
Mortality Classification Specialist
Health Statistics Division
Statistics Canada
R.H. Coats Building, 18th Floor
Ottawa, KIA OT6 Ontario
CANADA
Tel: 613 951 1648
Fax: 613 951 0792
E-mail: WoodPatstatcan.ca

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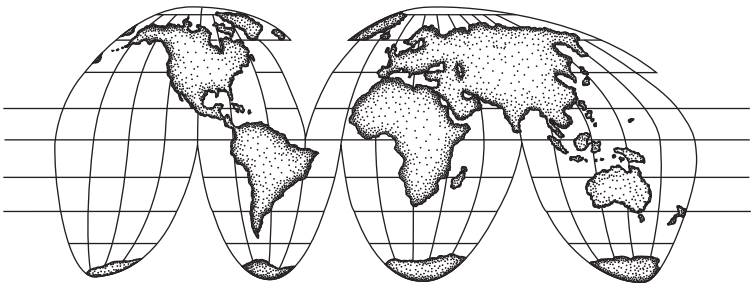


Welcome

Dr. Robert N. Anderson, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

On behalf of the planning committee, I welcome you to the third meeting of the International Collaborative Effort on Automating Mortality Statistics (ICE). I am sure that over the next few days we shall have some fruitful discussions that will help us all in our efforts to improve or implement automated systems in our respective countries.

Before we proceed, I want to be sure to acknowledge some of the people without whom we would not have been able to put together this conference: Ken Kochanek and Ari Miniño of the Mortality Statistics Branch at the National Center for Health Statistics (NCHS), Juan Albertorio of the Office of International Statistics at NCHS, Pat Drummond of the Office of Management at NCHS, the staff of Courtesy Associates, and Suzanne Howard who assisted on logistics.

I also want to especially acknowledge the contributions of Sam Notzon, who has been tireless in his efforts to make sure that this conference was organized and implemented. Also, let me acknowledge the members of the planning committee who put together the sessions and secured the speakers.

Now I would like to turn the podium over to Dr. James Weed, Acting Director of the Division of Vital Statistics at NCHS, who will provide welcome. Following Dr. Weed will be Dr. Ed Sondik, the Director of the National Center for Health Statistics.

Welcome

Dr. James Weed, National Center for Health Statistics, Centers for Disease Control and Prevention,
U.S. Department of Health and Human Services

It is a pleasure for me to greet you all as the Acting Director of the Division of Vital Statistics. I have served as Deputy Director of the Division for 19 years and only recently became Acting Director upon the retirement of Mary Anne Freedman this past February. The position of Director has been advertised, and now we are waiting to see who the next Director of the Division will be.

As most of you know, the United States has a decentralized vital statistics system. The registration of vital events in the United States is a State, and not a Federal function; thus, we have a total of 57 registration jurisdictions, including 50 States, the District of Columbia, New York City, and the 5 U.S. territories of Puerto Rico, the Virgin Islands, Guam, American Samoa, and the Northern Marianna Islands. Coordination of the U.S. national vital statistics system is based on cooperative relationships between NCHS and all of these registration areas. Uniform data collection is therefore critical if we are to have coherent and comparable national mortality statistics. The development and maintenance of the U.S. automated mortality medical systems—including Automated Classification of Medical Entities or ACME, Mortality Medical Indexing, Classification, and Retrieval or MICAR, SuperMICAR, and Translation of Axes or TRANSAX—has become an integral and routine part of what we do in the Division of Vital Statistics to ensure consistency in the classification and coding of cause of death among our constituent registration areas. We have accumulated a great deal of experience working with automated systems for coding cause of death over the past 35 years, and along the way we have benefited greatly from collaboration with other nations.

The ICE on Automating Mortality Statistics has been a tremendously successful forum for sharing the knowledge and experience that we have all gained working with automated systems. The previous ICE meetings in 1996 and 1999 were very productive and helpful for us in the United States, particularly with regard to reconfiguring our automated systems for the transition to the Tenth Revision of the International Statistical Classification of Diseases and Related Health Problems or ICD–10, and we are now preparing to release our 2001 mortality data for the United States. It is our third year of data coding using ICD–10.

As with previous ICE meetings, an important part of the purpose of our meeting over the next few days is to continue our collaboration with the goal of further improving our automated systems. Another important purpose of the ICE on Automating Mortality Statistics is to expand the mechanisms for technical support for those countries that recently implemented or plan to implement automated coding systems, with the ultimate goal of improving the international comparability of mortality statistics. We in the Division of Vital Statistics at NCHS are committed to the wide dissemination of the NCHS automated system, and also to providing training and technical support when and where needed. We are currently teaching annual courses for other countries in underlying and multiple-cause coding, and in the use and maintenance of the NCHS automated coding system. We plan to continue this training and support on an ongoing basis.

In closing, I want to wish you all a very successful and profitable conference. It appears to me that the agenda will provide the foundation for a very stimulating exchange of ideas and knowledge. So thank you very much and best wishes.

Welcome

Dr. Edward Sondik, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

I am Ed Sondik, the NCHS director, and I want to welcome you to Washington, to the United States, and to cherry blossom time. Sam Notzon planned very, very hard for you to be here at the peak of the cherry blossoms, and it is just about the peak time now.

This is one of our international collaboration efforts, and I see Harry Rosenberg here. I want to acknowledge Harry as a distinguished alumnus of the National Center for Health Statistics (NCHS) and of this effort. I am sure it is terrific for you to sit there, Harry, and look at the fruits of your labors.

These international collaborative efforts are now more than 20 years old, and this one began in 1995. In thinking about, as Jim said, how far back these automation efforts go, it is interesting how much of a part of the life of NCHS these have become. We actually are in the middle of a spate of efforts that is taking altogether about 5 years in which we are working at re-engineering essentially every system we have in the vital statistics system. We are working to make this more computer based than it has been in the past—entirely computer based, we hope, throughout the entire system both at NCHS and in every State. For all of the NCHS surveys, we are working on bringing those up to the state of the art in terms of informatics. As I was thinking about this, I was wondering whether the term ''automation'' may not quite be the most appropriate term these days. It seems like something more like ''informatics'' really gets at the sense of where we are. We are applying the information sciences so that it is not just about not requiring any human intervention; it should also enhance our ability to work with the information and the data so that it increases and improves the quality of what we have.

We have a couple of other efforts in the U.S. that relate to all of this. One is called the National Health Information Infrastructure (NHII). The NHII is a very broad effort to improve the way we handle information on health in the United States—the way we gather it and the way we disseminate it. Vital statistics is very much at the core of that. We have also recently produced a document called Health Statistics, a *Vision for Health Statistics for the 21st Century*. This effort, which took us several years to put together, gives us a set of goals and a vision for where health statistics can be in the United States in this new century. Many of us felt that health statistics was moving forward but that there was no real vision as to how we could organize it and best use the resources that we have. I think it is very important in any effort that you really have a vision so that you can see where it is you are going. Again, informatics, vital statistics, and automation play a crucial role in where this is going.

It is interesting that if we compare our efforts to those of other countries, many of which are represented here, some are ahead of the U.S. in these efforts. For others, perhaps we are a little bit ahead. What we do best with all of this in an international environment such as this is that we learn from one another. We in the NHII and in the vital statistics efforts looked at what was happening in other countries and felt that those activities were really models for us and influenced our direction to a great degree. What I hope is that we can expand these ICE efforts so that we can look even more broadly at the efforts in automation of mortality and in these other countries and compare and contrast among all of us so that we shall be able to track our progress and learn from one another. This effort, by the way, was widely discussed at a recent meeting of the Organization for Economic Cooperation and Development (OECD). It is always on the agenda.

As many have pointed out in the past, this is somewhat different from our other international collaborative efforts in that those tend to be focused on the analysis of data. The mortality ICE, in contrast, is really aimed at the production of data, how we go from, if you will, the field to actual production of data that can be used. And in that sense this is really a critical effort.

I, too, want to thank all of those who have been involved in organizing, implementing, and facilitating this meeting. I want to thank the funding agencies: the Soros Foundation, the U.N. Statistical Division, and the World Bank. All of them helped to finance the meeting. Also, thanks to the American taxpayer who also helped. And, to whomever found the Hotel Washington, congratulations. This is a very old hotel, obviously. I do not know what the rooms look like. I gather they look OK. While this is actually an extremely old hotel that has gone through many, many upgrades, it is now actually a very important meeting venue, the closest that one can get to the White House.

I want to thank Sam Notzon and Juan Albertorio of the International Office for their help in putting the meeting together, Bob Anderson, Ken Kochanek, and Ari Miniño of the Mortality Statistics Branch, and Pat Drummond, who worked so hard on the logistics. I also want to thank Bill Steiger for his support. Bill, who heads international programs for the Department of Health and Human Services, is going to be here this afternoon to give you his welcome. I wish you the best in this very, very interesting and very important area. I cannot tell you how important I think this area of informatics is to improving what we do, and to enabling us to actually collaborate more effectively than we have in the past. So welcome.

Logistics and Purpose of the Meeting

Dr. Sam Notzon, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

Good morning to all of you. It is a pleasure to be here and a pleasure to see all of you. Dr. Sondik wanted to know who was responsible for finding this hotel; it was our contractor, Courtesy Associates, who located this place, and we truly thank them. I am really pleased to see how many people are here.

What I want to do before I go any further is to recognize a couple of people. I am going to add to the comments that Dr. Sondik made about Harry Rosenberg. Harry, who is in the back of the room and whom most of you know very well, is truly the father of this ICE group. I think it is very safe to say that without him we would not be here today, certainly not talking about this topic. He devoted countless hours to making sure that this activity would be a success; he was instrumental in adding new topics and new people to the group, all of which were very key to keeping the ICE group fresh and moving forward. He devoted countless hours to working on this activity while at the same time taking care of his major responsibility overseeing the production, analysis, publication, dissemination of mortality statistics in the United States. So Harry, I do not know where you found the time, but we thank you very much for your efforts. They are to be appreciated. And just to show you how dedicated Harry is, he will be coming out of retirement later this week to participate in one of the panel sessions. So, that is yet another example of his dedication and interest in this topic.

Now the second person I want to recognize is Nina Schwalbe from the Open Society Institute, or the Soros Foundation, as we typically refer to it. Nina is the head of the health group within the Open Society Institute, and we want to thank her, in particular, for financial and other support. I am singling out the Open Society Institute because their contributions have been long standing; they have supported past meetings of the ICE and have shown exceptional interest in the application of automation to public health. The Open Society Institute has provided funds for automation training in the past for Hungary and Russia, and you will be hearing about some of the results of that effort. At the present time, the Open Society Institute is providing support to the ICE not only for this meeting but also for training and technical assistance to those countries of Central and Eastern Europe that have an interest in automated coding. In this activity NCHS and other members of the ICE will collaborate with the Open Society Institute and with the statistical organization of the European Union in providing assistance to the central and eastern European regions. So Nina, we deeply appreciate your interest and support for the ICE and, more generally, for the application of automation to public health.

Returning to the purpose of the meeting, our goal is to provide information on the use of automation for mortality statistics to all of the meeting participants and beyond them to the community of interested parties around the world. Under this general heading there are some specific items that we hope to accomplish: 1) We want to review the accomplishments of the ICE and its member countries since our last major meeting in 1999; 2) We want to consider other developments that have taken place outside the ICE but that are relevant to its objectives; and 3) We want to discuss future activities that the ICE should consider.

Now I would like to provide you with some background on the ICE. I think it is important to understand what this effort is about before we get into the technical sessions. So for those of you who have been to previous meetings this will be something of a review, while for those folks who are new to the ICE, I think this will help to put the following presentations into context.

The specific objectives of the ICE on Automating Mortality Statistics are as follows: to share knowledge and experience in automated systems for coding mortality data, to develop and improve existing automated systems through collaboration, to examine the transition to ICD–10 for mortality, and to expand mechanisms for technical support. The overall goal of the ICE is to improve the quality, timeliness, and comparability of international and national mortality statistics.

When the ICE started in 1995, the initial objectives were to promote information exchange in automation and to attempt to share the burden of international demands for technical assistance on automated mortality

coding systems—something that seems to be growing by the day. Among other things, the ICE functions as a users' group for the countries currently using automated coding systems. Members of the group exchange information on automation and on its use for mortality data. Working collaboratively or individually, group members develop new ideas in the area of automation and work through the testing and evaluation of those ideas.

The first meeting of the ICE was in 1996 in downtown Washington; the second, in 1999, was in Bethesda, Maryland. At the 1996 meeting the participants produced recommendations on a number of topics related to the use of automation in mortality statistics. Some of those recommendations were intended for individual countries to pursue while others addressed issues that the ICE as a whole should take up. The recommendations were grouped into six broad categories that formed the basis for the activities of the ICE. Even though some time has passed since that initial meeting, it is amazing to see how relevant most of these recommendations remain. The recommendations also provided a useful framework for reviewing activities of the ICE and for previewing the content of the technical sessions that you will occur over the next three and a half days.

The recommendations from the first ICE on Automation meeting were grouped into six major categories as follows: nosology and the training of nosologists in an automated environment; decision tables and mechanisms for updating them; data quality and editing; training and mechanisms for technical support; language issues; and implementation issues. We can use these topics to focus on the activities of the ICE, in particular to assess progress since the last meeting. So let us go through these recommendations to see what has been accomplished. For your convenience, you will find a copy of the original recommendations in your packet.

The first group of recommendations concerns the changing need for nosologists in an era of automation. National and statistical offices that have automated their cause-of-death coding are facing the conflict of needing fewer coders but simultaneously requiring more skilled nosologists to deal with the complex issues raised by automation. Countries are faced with the dual problems of improving the skills of their nosologists and raising their status and salaries. NCHS has addressed the skills issue by establishing an intensive international training program for countries planning to implement automated mortality coding. NCHS has offered this course three times and will continue to offer it annually to mortality coders worldwide. In fact, we have at least four graduates of that course here with us today.

Regarding the status of nosologists, this issue was raised with the Heads of the WHO Collaborating Centers for the Classification of Diseases. In 1999, the Center Heads agreed to the establishment of the Training and Credentialing Subgroup to take up these issues. Marjorie Greenberg has served as a chair of this subgroup since its inception. Among its purposes are to develop a training and credentialing program for mortality and morbidity coders that will be presented to the 2004 meeting of the International Federation of Health Records Organizations to seek their endorsement. We hope that gaining IFHRO endorsement will be an important step in raising the stature and salaries of nosologists, which in turn will help attract qualified personnel and retain the most skilled nosologists. Please note that the ICE conference session on training, which takes place on Wednesday afternoon, includes a number of presentations on issues related to the training of nosologists, including a report by Marjorie on the progress of the WHO Training and Credentialing Subgroup.

The second group of initial ICE recommendations concerns decision tables, their comparability, and mechanisms for updating them. Regarding the comparability of decision tables, England, France, and Sweden, all of whom are member countries of the ICE, collaborated with NCHS on developing the ICD–10 Decision Tables for the U.S. automated mortality coding system. This is a perfect example of international collaboration. Some discussion of decision tables will take place in the first technical session of the ICE meeting, immediately following this presentation.

Regarding consistency in the interpretation of coding rules, the ICE proposed the creation of a body to identify problems of interpretation and inconsistencies in the ICD, and to propose solutions. Such a group was recommended to the WHO Center Heads, which led WHO to formally endorse the Mortality Reference Group (MRG) in the late 1990s and to designate its members with Harry Rosenberg as the first chairperson. The

MRG works directly with the WHO Update Reference Committee to make recommendations on needed updates and corrections in the ICD to the Center Heads and WHO. The MRG has taken on an increasing number of problems with the ICD, most of which arose from discussions in the online mortality forum sponsored by the Nordic Center. The MRG reports annually at the WHO Center Heads meeting and actually met last week, since many of the members of the ICE are also members of the MRG.

This group of recommendations also covers the need for comparability studies to assess changes from ICD–9 to 10, from manual to automatic coding, and on annual changes to ICD–10. Many countries have completed their ICD–9 to 10 comparability studies, and some have also looked at the effect of switching from manual to automated coding. You will hear presentations from several countries about their comparability studies in the first session on Wednesday morning.

The third area of recommendations concerns data quality and editing. The ICE focused on the need to educate physicians on their role in completing the medical certification of cause of death, recognized the need to make training materials broadly available, and emphasized the importance of data edit procedures. Since the first ICE meeting, the potential of electronic death registration for improving the quality of cause-of-death information has been recognized and endorsed by the ICE. A number of countries have attempted to improve physician certification via training, and EuroStat is launching its own effort as well. I might mention that Harry Rosenberg and Julia Raynor recently led a training course in Hungary, which had this objective among others. A few countries have begun to develop and test electronic death registration systems, and these experiments are being followed with great interest. The issues of data quality and editing will be addressed in several sessions of the meeting, including the electronic death registration session this afternoon, and the data quality session on Wednesday morning.

The fourth set of recommendations is related to training for automation support and to mechanisms for technical support. Automated systems will not work, or will not work well, unless coders and managers receive the training they need. Medical coders will need to learn a new approach to coding, and as a part of this will have to learn how to work with personal computers. Managers will need training to ensure that the automated processing proceeds in an orderly fashion, and will need to learn how to deal with system problems.

In addition to national training courses, NCHS has addressed both of these issues with an international training course mentioned earlier. The international course is designed to train trainers, and will be useful to any country considering the use of an automated coding system for mortality data. The course, which is offered at the NCHS coding facility in North Carolina, provides intensive training for nosologists in multiple-cause coding and underlying-cause coding. The course includes a 3-day, PC managers' course to address the managerial issues associated with automated mortality systems.

Many of these issues will be covered during this third meeting of the ICE, particularly in the next session on automated coding systems, as well as in the training session on Tuesday afternoon. In addition, mechanisms for technical support will be the focus of the Thursday morning session on knowledge and data dissemination. Let me call your attention to the online bulletin board established by the Australian Bureau of Statistics to share information and experiences related to automation and mortality statistics.

The fifth group of recommendations concerns language issues. Some components of automated coding systems, such as the Decision Tables, are not affected by language because they are based on ICD–10 codes. This is true with the ACME system developed by the U.S. to select the underlying cause of death from information on all causes of death reported on death certificates. Many non-English speaking countries have used the ACME system successfully for many years. However, other components of the U.S. automated system, such as MICAR and SuperMICAR, are language dependent. These parts of the U.S. system cannot be used directly in non-English speaking countries and are not easy to convert to other languages.

The ICE recommendations on language focused on the importance of sharing experience and knowledge and the development of language-dependent front end systems. Since the first ICE meeting, interest in automated coding systems has spread to many non-English speaking countries, greatly increasing interest in the development of a language-independent automated system. While automated systems may never be completely language-independent, the idea is to make as much as possible of the automated system language-independent in order to simplify the development of automated systems for different countries and

languages. This is a particular concern of the European Union, which would like to see automated coding used in all its member countries, but is faced with the need to develop systems in 15 different languages. We shall have extensive discussion of language issues in the first session tomorrow morning, where several countries will describe their experiences in developing automated systems and where you will learn more about MICAR and SuperMICAR, the front end systems used in the U.S. Some of these issues may also be discussed in today's next session, which provides an overview of automated coding systems in several countries.

The final set of ICE recommendations from the 1996 meeting concerns implementation issues. Recognition was given to the importance of WHO involvement in automation implementation, and to the benefits of having Web sites and language-based e-mail groups to expand the availability of information on automation. A final recommendation urged the ICE to create a formal users group on automated systems.

Many of the recommendations of 1996 have been implemented. The ICE created a users group, which shortly thereafter led to the establishment of the ''Electronic Tools Committee'' system users' subgroup by the WHO Center Heads. The Australian Bureau of Statistics has created an automation bulletin board. France and Canada have established a French language e-mail group. Several countries that are part of the ICE are actively involved in providing technical assistance to countries interested in automated coding systems. The effort to assist countries of Central and Eastern Europe with this technology is occurring under the joint sponsorship of EuroStat and the ICE. Many of these activities and others will be addressed in several of the conference sessions presented over the next few days.

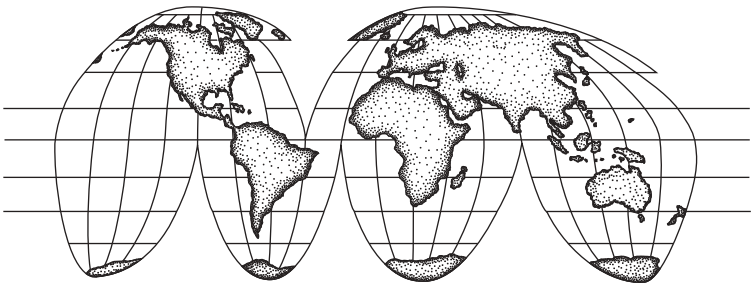
Since the first ICE meeting in 1996, the ICE planning group has considered a number of other topics to pursue in the area of automation. Some of these topics will be addressed in two remaining technical sessions of this conference. The first is a session on Tuesday morning on electronic tools. The concept of electronic tools arose at a meeting of the WHO Center Heads but was added to the activities of the ICE because of the obvious relationship of electronic tools to the concept of automation and its ready application to items of great importance for automated coding of mortality data. For example, the use of electronic media is ideal in the dissemination of large documents such as ICD–10, and its national adaptation for morbidity coding, as well as applications for electronic publishing and others.

Another topic that has always been an important interest of the ICE but was not directly part of the original recommendations is the issue of multiple cause-of-death data and its analysis. This afternoon we shall have several presentations on the issue of multiple-cause coding and on the analysis of the resulting data. As someone who likes to analyze data myself, I have to say that after all the hard work and thought put into preparing mortality data, it will be nice to see what can be done with the data, particularly with information on multiple causes of death.

In closing, I would like to go back to the purpose of the meeting. We hope to review recent accomplishments in the area of automated coding and mortality data, and we want to discuss future activities that the ICE should consider. I would encourage all of you to review the list of recommendations, to listen carefully to the presentations over the next three and a half days, and to come back ready to make comments during the final session on Thursday morning on prospects for the future of the ICE group. Thank you very much.

SESSION 1

Overview of Automated Coding Systems



Overview of Automated Coding Systems

Donna E. Glenn (moderator), National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

We are going to provide an overview of existing automated systems, where they stand now and where they plan to go in the future. We have a total of seven different speakers: Lars Age Johansson, Gerard Pavillon, Dr. Ruy Laurenti, Dr. Moriyo Kimura, Juan Antonio Ortega Garcia, Sulaiman Bah, and Ed Elliott, who will, respectively, present information on the systems of Sweden, France, Brazil, Japan, Mexico, South Africa, and the U.S.

Use of Automation in Sweden

Lars Age Johansson, Board of Health and Welfare, Sweden

I will give you a short overview of how we implemented automated coding in Sweden. In Sweden, we have used automated coding since 1987. First we implemented ACME for the selection of the underlying cause of death. A few years later, we introduced a system for automated coding of multiple causes of death, which is the input to ACME.

The main reason why we decided to introduce ACME was that we had gross inconsistencies in the selection of the underlying cause. When we made a review of our statistical trends for the 1970s, we found that about half of the trends in our statistics were artifacts, and simply due to inconsistent selection of the underlying cause of death. That, of course, made analyzing Swedish statistics very exciting, but most epidemiologists working with our data were not quite that enthused. So we introduced ACME. Later we found that there were some inconsistencies in the multiple-cause coding as well. At first when we introduced ACME, people had to code the input to ACME manually, and those of you who have tried ACME coding will know that it is not quite straightforward. There are a quite a few things you need to think about: some codes have to be modified and related to other conditions on the death certificate just to make it clear to ACME what has happened. And if you miss any of those modifications, ACME will select the wrong underlying cause.

In the second step we introduced a multiple-cause coding system which we called the MIKADO. The main reason for doing that was to get rid of some inconsistencies in the multiple-cause coding. Our managers also had a hope that we would save some money on it. We succeeded very well in achieving more consistent data, and after a couple of years we achieved a coding error of less than 2.5 percent in the selection of the underlying cause. When we made our first measurement a few years before we introduced ACME, the error in the selection of the underlying cause was about 25 percent, so the 2.5 percent meant a great improvement. We did not save very much money, and the main reason for that, of course, was that data entry became much more expensive. Before we introduced automated coding, the typists only had to enter the codes, but now they have to enter complete medical terms, sometimes very long, sometimes quite difficult to understand.

Our system has four main steps. First we have the text entry to get the diagnostic terms from the death certificates into our system in some way. We then put them into a mortality database, and we then retrieve data from the mortality database for coding and other processing. In the coding step, we first do the multiple-cause coding and then input the multiple causes into the ACME system and select an underlying cause.

We first scan the death certificates, and with an optical character recognition software called Eyes and Hands we try to interpret as much as possible of the text from the death certificates. That works fairly well with typed death certificates and about 45 percent of our death certificates are typed. It works less well with hand written certificates, of course. So we have professional typists who review the text after scanning and correct them. We have about 100,000 deaths a year in Sweden, and we need three or four people to do the scanning and to edit the text.

We put the text into a database called MILAGO. We have used this database, which was developed in Paradox for Windows, since 1998. It is basically a data flow manager, which keeps track of what has been done and what needs to be done for each death certificate in the database. We use it to extract workloads for the multiple-cause coding or the underlying-cause coding. We also use it for editing, for producing our annual files, to produce tables, and to retrieve data. To retrieve data we can use either ICD codes or medical terms in free text.

The next step is to do the multiple-cause coding, for which we use a software developed at Statistics Sweden in the early 1980s. Called MIKADO and developed in Paradox for DOS, it was first used in 1993. MIKADO assigns an ICD code to each medical term on a death certificate. When necessary, it will also modify the code according to the instructions for ACME input coding. We use it to produce the input files for ACME processing. In some ways, MIKADO differs from the American multiple-cause coding software called MICAR. The main difference is that we tried to make MIKADO as similar to manual coding as possible. The software presents the entire death certificate to the coder, and the coder can approach the problems and solve

them in any order and in any way he or she likes. For example, you do not have to sort out all spelling errors before you move on to the code modification problems. You can also assign an underlying cause at this stage if you like.

We have a quite compact dictionary with only about 7,000 terms, which is considerably less than in most other automated coding systems. But we have spent much time on developing a language standardization procedure, so even with those 7,000 terms we cover about 90 percent of the entries on the death certificates. I will get back to how we do the language standardization tomorrow. We do not use the Entity Reference Numbers (ERNs). I will also discuss tomorrow why we do not, and which problems we encountered when we tried to introduce the ERNs.

As I said, the MIKADO is a DOS system, and it becomes more and more difficult to run DOS systems under Windows. Together with France, we are planning to develop a replacement for the MIKADO. I am not quite sure about the timeframe, but it will take us perhaps another two or three years. For the underlying cause we use ACME. There is simply no alternative to ACME for selecting the underlying cause.

I would like to finish with a few wishes for the future. I think our main wish is for a fully integrated system where you use the same system for data entry, multiple-cause coding, and selection of the underlying cause—in short, one similar to manual mortality coding. As soon as you have entered the multiple causes, the system would tell you what the underlying cause would be, and you could at once evaluate whether the underlying cause is reasonable or not.

We would also wish for a system that is somewhat easier to maintain than our present one. As I said, you have to make some modifications to the input codes in order to make ACME really understand the sequence. Currently, it is very easy to miss some of those modifications when you try to develop a multiple-cause coding system of your own. When there are changes to the MICAR system that affect the ACME input, the changes are well documented by the NCHS. However, in the wealth of information that you get with every new version of ACME, it is quite easy to miss some things. What we are looking for and hope to develop is some way to import the code modifications from MICAR into this new software. If we could do that, I think we will have a mortality coding software that is efficient, easy to use, and maintains international comparability.

Thank you very much.

Use of Automation in France

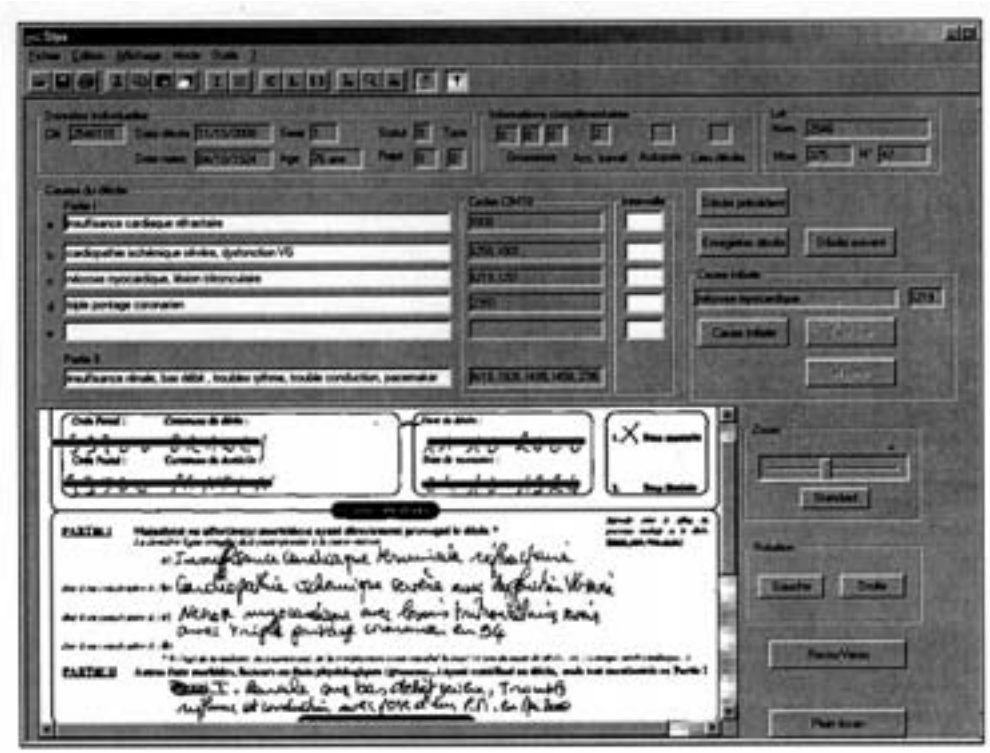
Gerard Pavillon, National Institute of Health and Medical Research (INSERM), France

I will make a presentation on the automated coding system used in France for medical causes of death. This system is called STYX. There were several motivations for implementing this automated coding system. 1) The first one was linked to the implementation of ICD–10. French coders have been working with ICD–9 for 20 years, and ICD–10 totally renews the structure and the codes. ICD–10 rules for the selection and modification of the underlying cause of death are also much more complex than ICD–9. 2) The second motivation deals with data quality. There are differences between coders on coding and underlying-cause selection. These differences would have been increased by implementation of the new revision of the ICD. 3) The third motivation is the international comparability of mortality data. ICD does not include all the information needed for coding, and there is place for interpretation. Automated coding systems require the precise coding of each diagnosis mentioned on the death certificate. All the causal relationships needed to apply rules for the selection of the underlying cause must also be specified. From this point of view, automated coding systems can be more easily standardized. 4) Another motivation is paper document management. We have about half a million death certificates a year; it is a large amount of paper to manage. Technology now makes it possible to digitize documents and to have them available online for consultation.

On the basis of these motivations, we determined the specifications of our system. First, as we wanted to include this system in the general electronic document management system, we have designed specific software. We tried to conceive a highly interactive and friendly system. We also wanted a transparent system that is able to explain what it is doing. In order to achieve the international comparability goal, we include ACME Decision Tables in STYX. This means that ICD–10 rules are applied on the same knowledge basis as in ACME.

The following schema shows the principle of the whole French system. We first get a database of the picture of the death certificates. Then, using optical character recognition, we get a database of individual data. The problem then is to key in medical diagnoses. Medical causes of death are written in such a way that it is impossible to use optical character recognition systems. We have implemented vocal capture and find that it works very well; it is quicker than key entry, and it avoids spelling mistakes. At the end of this process, we get the medical-cause text, the medical-cause codes, and the underlying cause-of-death codes.

This slide shows the interface of STYX. On the bottom is the picture of the death certificate. On the top is the individual identifying information and demographic data, and below this (in the middle panel) is the medical part of the death certificate. To the left of the middle panel is the text for causes of death and on the right of that are the corresponding ICD–10 codes.



STYX manages the capture of diagnoses text, ICD–10 coding, and the selection and modification of the underlying cause of death. STYX is able, on request, to explain the ICD–10 rule sequence applied to get the underlying cause. For different reasons, STYX can reject a death certificate, which is denoted when a death certificate is flagged as problematic. This means that it must be reviewed by a senior coder. Certificates can be rejected for a number of reasons. One reason is that the ICD code is unknown, which occurs when the diagnoses text is not included in the dictionary. Other death certificates are rejected because they are not properly completed; for instance, when we have no information about the external cause (suicide, homicide, or accident) in case of violent death. We also reject for manual check all the newborn deaths.

When we started to implement STYX, coders had many problems to get accustomed to this totally new way of coding. I think that STYX is now better accepted mainly because coders see that there are always difficult cases that must be checked and even manually coded.

Thank you.

Brazilian Diagnosis Coding System

Dr. Ruy Laurenti, WHO Collaborating Center, University of São Paulo, Brazil

Introduction

Brazil has a long tradition in the production of mortality statistics. It is possible to recover mortality data from the last decades of the nineteenth century for several state capitals, especially in the South and Southeast regions. Currently, about 80 percent of the Brazilian population lives in urban areas, and the number of deaths registered is around 950,000 per year, representing 85 to 90 percent of the total. In the South and Southeast regions, the coverage is almost 100 percent. However, in the Northeast, these figures are around 60 to 70 percent and in the North—the Amazon Region—registration completeness is around 50 percent. The difference in coverage of death registration reflects the sociodemographic differences among these regions. Brazil, as a continental country, is geographically heterogeneous in socioeconomic and demographic aspects, as well as in the availability of services including health. While the South, Southeast and part of the Middle-West regions have many resources, the North region (the Amazon region) lacks resources. It represents 60 percent of the national territory, but only 10 percent of the population. This huge area, with extremely low demographic density, faces difficulties in communication, transportation and service organization, which strongly impacts the production of statistics not to mention the availability of both quantitative and qualitative human resources.

ICD use and cause-of-death coding

By the end of the nineteenth century until the first years of the last decade of the twentieth century, the state capitals produced mortality statistics. At the time, health services were decentralized, and each municipality generated its own statistics, requiring a great number of coders of causes of death. Since the nineteenth century, the ICD and all its revisions have been used to present statistics on the cause of death. Although ICD has always been used, no attention was paid to the certificate, to coding rules, nor to data quality. Almost nothing was invested in training medical coders. In 1950, the ICD–6 was adopted in Brazil, together with the International Form of Medical Certificate of Cause of Death. From then on, the underlying-cause-of-death coding followed the ICD–6 standards and rules.

In 1964, the School of Public Health of the University of São Paulo started to train coders for all Brazilian states. In 1975, the Mortality Information System (Sistema de Informaço em Mortalidade-SIM) was created at the national level whereby the states send their spreadsheets with mortality data to the Ministry of Health that periodically publishes them. There is a 2-year gap due to the evaluation phase for data consistency. Data forwarding to the Ministry of Health is done partly via Internet and partly via floppy disk. In 1976, the WHO Collaborating Center for Classification of Diseases in Portuguese, known as the Brazilian Center, was created.

A team of experts in health statistics, coordinated by the Brazilian Center and the Ministry of Health, began to work hard to strengthen the Mortality Information System (SIM) and train human resources. We were able to achieve a higher quality in coding the cause of death, although some difficulties remained in the North and Northeast regions. In addition to training mortality coders, the Brazilian Center inspects the coding service and, most importantly, evaluates the coders. It also prepares manuals to guide coders, as well as training materials on proper completion of death certificates for physicians and medical students.

Coding cause of death electronically

In 1978, the Brazilian Center showed interest in implementing the ACME system. With the support of the National Center for Health Statistics from the United States, it started to foster the use of ACME in the state

of São Paulo, which happened in 1983. The result of using the ACME system in the state of São Paulo was so good that the Ministry of Health tried to implement it in all Brazilian states. However, due to several reasons, it was not possible. To implement ACME, the Brazilian Center made some adjustments to the Decision Tables to meet the Brazilian reality, such as to accept some sequence and to transform a ''poor defined'' diagnosis into well-defined according to what was known by the physicians from the Brazilian reality in the statement of cause of death. ACME was only used in the state of São Paulo since it would be easier for the Brazilian Center to supervise it. In 1993, the Brazilian Center, together with professionals from the Ministry of Health, established the basis for developing a computerized program similar to ACME. This was necessary because the death-certificate coding that used to be performed only in the state capitals would now be done at the municipal level. With more than 5,000 municipalities, there was the need to train coders and ensure the quality of these data. Then came the idea of developing software to electronically select the cause of death. The software that was developed is known as SCB.

The ACME (modified) Decision Tables were used in SCB for deaths between 1994 and 1995, but related to ICD–9. In 1996, after a change in the program, the SCB selected the cause according to ICD–9 and translated the code into ICD–10. This brought some problems, especially in the number of mistakes in the underlying cause that were corrected as identified.

In 2001, the Brazilian Center concluded that it was important to develop a new program since the programming language used (PROLOG) was considered obsolete. With the decentralization of SIM and the addition of SCB in the official software for entering data in the mortality system, it was decided to use a faster program. This change would allow the use of decision tables and underlying cause according to ICD–10, leaving aside the ICD–9/ICD–10 transition phase. The development process for this new version was based on the NCHS Instruction Manual (Volume 2, ICD–10) and on the ICD–10 Decision Tables provided by NCHS. The resulting program is the SCB WIN (Windows version) using Delphi language; it meets all rules, standards, and guidelines in Volume 2 of ICD–10 and the ICD–10 Decision Tables. In order to make the system dynamic, we developed the SCB GERENCIAL that allows for maintenance and adequacy of databases used by SCB WIN.

After SCB WIN and SCB GERENCIAL were approved, we developed the SCB WEB (Web version) that provides online processing via Internet, integrated with SIM WEB. It can also be used locally, integrated with the SIM WEB via electronic media (diskette). This process was completed in 2002 and is currently in its testing phase. We expect to have it up and running in the second half of 2003. Although the SCB is being used all over the country, we still face operational difficulties in some regions, particularly in the Amazon.

Automated Coding of Diagnostic Expressions and Selection of Underlying Cause of Death (ACSEL) System in Japan

Moriyo Kimura (presenter), M.D., M.P.H., Ministry of Health, Labor and Welfare, Japan; Kazuko Takemura; Hibiki Ueda, B.A.; Hiromi Takeuchi, M.D., Ph.D.; Ryuji Agematsu, M.D.; and Tetsuya Tamura, Ph.D.

Background

Japan has a centralized vital statistics system in which every death record function is carried out under the Ministry of Health, Labour, and Welfare. The development of the automated coding system took place in 1989. The new system, ACSEL (an acronym for ''Automated Coding of Diagnostic Expressions and Selection of Underlying Cause of Death''), was implemented in 1995 without delay in ICD–10 adoption and has been used up to now.

This new system was needed mainly because of different circumstances between ICD–9 and ICD–10: (1) the number of diagnostic terms doubled from 7,000 to 14,000 and the expected combination of coding patterns drastically increased, (2) new concepts were introduced, for example, Rule 3 interpretation, malignant neoplasm of independent multiple sites, etc. The ACSEL system was designed with two goals: (1) to use a computerized system that gives appropriate ICD–10 codes and selects the underlying cause of death (UCD) embodying the selection rules with satisfactory matching level of manual coding, and (2) to simplify data entry and reduce the burden on medical coders. The second goal was practically important because our governmental officers stay in one position for a short period, usually three to four years, and human resource skimming is a nationwide problem. Thus, an effective system that would not need specially-skilled personnel was necessary. Under the old automation coding system in ICD–9, around 30 percent of events were not automatically assigned, and manual coding was needed for those cases.

ACSEL system

The concept of this new system was based on the U.S. automation coding system (MICAR, ACME, TRANSAX) but the structure was unique in order to be suitable to our vital statistics system.

Data entry

For the data entry system, we use Optical Character Reader (OCR). Local municipalities fill out the death statistics forms using death data from death certificates and send the forms to each prefecture for the second verification. Finally, all forms are gathered in the Ministry of Health, Labour, and Welfare and are scanned by OCR. Because of the variety and difficulty of reporting, external causes and clinical procedures are handled manually.

Data editing

The actual ACSEL system starts from this stage when causes of death (COD's) are entered in Japanese. It is usually necessary to make corrections, e.g., correcting misspellings and modifying characters. Since we use four different types of characters (Chinese, Hiragana, Katakana, Alphabet), the ACSEL system performs various types of character conversion.

Phase I

As MICAR generates the multiple-cause ICD codes, Phase I is for applying an ICD–10 code to every reported cause. ACSEL separates causes into elements. An element is a 6-digit number, which is similar to an

entity reference number (ERN). However, this is not equivalent to ERN but the word that can best signify a certain condition independently in ICD–10. The broken-up elements are combined together to indicate a cause. We call it an ''element code.''

Example:

	Right acute pneumonia		
Elements	Y00004	D00297	A00493
Element Code	Y00004 +	D00297 +	A00493

The repeated-elements matching is done until appropriate ICD–10 codes are assigned in the dictionary.

Phase II

ACSEL then applies the WHO rules for selection of the underlying cause of death (UCD) in ICD–10 as ACME does. The first step is to determine a ''tentative'' underlying cause (TUC). Once TUC is decided, modification rules are applied to determine an UCD. Since we have substantial reporting of ''heart failure,'' our rules take this into account. We also carry out neoplasm coding during this phase.

Data correction

ACSEL has two types of error messages: ''warning'' and ''rejection.'' Two re-entry procedures are possible if these error messages appear: (1) re-entry to Phase I using corrected cause-referring death registration forms, and (2) direct ICD–10 correction in Phase II. This stage is very unique and useful because even unskilled coders can observe the erroneous results easily.

Accuracy

With ACSEL, 98.8 percent of death records are automatically processed. According to the data of November 2002, the underlying-cause assignment was applied with the match rate of 92 percent when compared with manual coding. The match rate was much better if trivial errors such as misspellings are corrected prior to matching.

Quality control and quality assurance

We have roughly 970,000 deaths annually. One hundred percent of automated coding assignment is reviewed and double-coded by medical coders.

Maintenance

Error checking and updating the dictionary are done on monthly basis.

Issues

With ACSEL, 98 to 99 percent were automatically coded in ICD–10 as of 2002. Our comparability study in 1995 showed that overall agreements between automated coding assignment and manual coding in the ICD–9 system and ACSEL (ICD–10) were 71.4 and 95.4 percent, respectively. Even with the drastic improvement in agreement from the previous automation system, there is still room for improvement.

Another issue is external cause of death and clinical procedures, for which programming has not yet been completed. New programs with equal throughput and a match rate comparable to the current system need to be developed.

Automation of Cause-of-Death Coding in Mexico

Juan Antonio Ortega García, Demographic and Social Statistics Office, National Institute of Statistics, Geography, and Informatics (INEGI), Mexico

Objective

The purpose of this paper is to present the main advances of the project for Automation of the Cause-of-Death Coding in Mexico through the adaptation of the Automated Coding Systems of the United States' National Center for Health Statistics (NCHS). We will also show results of the Preliminary Consistence Study between the Automated Cause-of-Death Coding using the Mortality Medical Data System (MMDS) and the traditional manual coding procedures still in operation in Mexico.

Background

Among other things, the Demographic and Social Statistics Office of the National Institute of Statistics, Geography, and Informatics (INEGI) of Mexico generates information about registered deaths in the Nation. Involved in this is the important process of coding causes of death, which up to now has been done manually. This takes a lot of time, is expensive, and is exposed to the risk of systematic errors. Besides, manual cause-of-death coding is one of the most difficult tasks with which every national office of vital statistics worldwide deals. In mortality statistics, specifically coding cause of death, it is very important to implement automated systems because of the complexity in the rules and structure of the International Classification of Diseases (ICD), which is the statistical classification system promulgated by the World Health Organization (WHO) for coding mortality, morbidity, and problems related to health. Automation of coding causes of death in Mexico has the objective of homogenizing criteria, improving the quality of statistical information, and making available data for multiple-cause-of-death studies. Automation also permits us to take better advantage of the underlying-cause-of-death coders' experience by setting the rarest and the most difficult cases under these coders' responsibility, thus allowing them to dedicate more time to design strategies for improving coding and for reviewing the ICD coding criteria.

Procedure

To adapt the SuperMICAR input data module of the MMDS, it was necessary to gather the more common textual descriptions of the causes of death in Mexico, thereby identifying patterns of describing pathologies reported on the death certificates. A random single sample was taken of 39,881 certificates from the registered deaths in January 2000. This represented 8 percent of the total deaths in Mexico during 2000. Textual descriptions of the registered pathologies in Part I and Part II of the death certificate were captured, as well as the ICD–10 codes assigned manually to every morbid entity. This information was the basis for the Spanish terms added into the SuperMICAR Dictionaries to produce inputs for the MICAR200 and ACME modules that would be used for the automated coding and selection of the underlying cause of death.

Results

We added a total of 4,094 categorized words to the system tables, words that conformed with 19,649 descriptions of several pathologies from the sample. The sample's certificates show an average of three causes of death, in contrast with the single underlying cause of death that INEGI produces for each death under the manual system. As part of the system tests, data from each certificate were introduced to the MMDS SuperMICAR input module; the variables included were sex, date of death, age, cause of death (Parts Ia, Ib,

Ic, Id, and II), and duration of pathology. From 39,881 certificates, which contained a total of 112,222 descriptions of causes of death, the SuperMICAR module accepted 31,954 (80 percent of total certificates) with a total of 102,989 pathologies (92 percent of the total pathologic terms). Rejected certificates contained some kind of term or word that was not added into the database or not referenced to a corresponding term in English. On the other hand, the MICAR200 module rejected almost 340 certificates due to insufficiently specified descriptions of external causes. Thus, the ACME module processed 31,215 and rejected 1,750 certificates due to several processing errors, finally achieving 29,477 processed records that were free of errors and whose underlying cause of death was automatically selected by the system. The following are results for the sample of 39,881 certificates of death.

1) 73.91 percent of the certificates (29,477) were successfully processed to produce the codes for the underlying cause of death; these codes were assigned automatically by the system.

2) For 26.08 percent of the certificates (10,404), it was not possible to assign a code for the underlying cause of death. This was basically due to the certificate having a pathologic term that the MMDS could not process because of some unknown word or some other kind of error. As a result, the whole certificate was rejected.

One way of evaluating the effectiveness of cause-of-death coding and underlying-cause selection by the MMDS is to make a comparative study between both procedures by measuring consistency levels in the coding methods. The following consistency scheme was used, similar to that used in other international studies.

a) ''Accurate concordance at four digits'' or perfect concordance of assigned codes by both coding systems at the four-digit level.

b) ''Accurate concordance at three digits'' or a perfect match of codes assigned by the two coding systems at three digits of coding (that is, at the category level).

c) ''Concordance at group'': where two coding methods match at least at the group level of causes.

d) ''Discordance'': when both coding methods, manual and automated, do not coincide either at the group or category level.

The main results are presented as follows:

1) 57.2 percent of the certificates coded by the MMDS have a code for the underlying cause that matches exactly with the code manually assigned by the coders of the Institute.

2) 67.68 percent of certificates coded by the MMDS have codes that coincide at the first three digits with the manually assigned code.

3) For 77 percent of certificates coded by the automated system, there was a match for the two first digits of the code.

4) Discordance in the codes for underlying cause between manual and automated coding represents 18.03 percent of certificates coded by the system. The level of discordance does not necessarily mean that the automated system is wrong in selecting the underlying cause for these cases; it could mean that the relation of Spanish terms with English terms is not yet suitable or that the manual assignment of the underlying cause may not adhere to the international criteria programmed into the MMDS. It is necessary to analyze the discordant set of certificates and determine whether the system failed or the manual code assignments were incorrect.

5) For those certificates whose underlying cause did not coincide with those of either coding procedure, a total of 5,317, we found that some of the pathologies reported in the certificate matched with the manual coding. Thus, for 26.37 percent of these 5,317 certificates, five of the causes reported on the certificate were correctly coded; for 28.39 percent, at least four causes had ICD–10 codes that coincided between both coding procedures. For almost 60 percent of the certificates, at least one of the causes of death coincided with the manual coding. In the case of those certificates for which four or five causes of death

are well coded, that is, the codes of both the manual and automated procedures matched, it is probable that only the underlying cause selection was different because the manual coding did not adhere to the international rules.

A revision was made of the pathological terms and codes of those certificates that particularly presented differences in the underlying cause of death coding between both coding procedures. Nevertheless, it was not possible to review the selection of the underlying cause by the time this document was prepared. One thousand four hundred thirty two pathological terms were analyzed, obtaining the following results:

1) For 101 terms (7.05 percent) a greater analysis is required since they are insufficiently specified causes, and it was not possible to determine which coding method was successful.

2) For 303 of the pathological terms (21.15 percent), manual coding was the right method, while the automated system assigned an incorrect code.

3) For 1,028 pathological terms (71.78 percent of the 1,432), the MMDS system accurately assigned the ICD–10 code, while the coders assigned a wrong code by manual techniques.

Conclusions

73.91 percent of the certificates have an underlying cause of death assigned by automated media. The coding and selection of the underlying cause of death matched on 3 and 4 digits (as measured in other similar international studies) in 67.68 percent of all introduced certificates. The causes in chapters V, IX, X, XIV, XVI and VXIII—medical entities such as mental and behavioral disorders; diseases of the circulatory, respiratory, and genitourinary systems; certain conditions originating in the perinatal period; and symptoms, signs, and abnormal clinical and laboratory findings not elsewhere classified—have the best matches. Automated coding and the selection of the cause of death associated with these pathologies was completed successfully for around 95 percent of the records, because for these groups of causes the current coding ratio is larger than 0.95. There were lower coding ratios for violent and accidental deaths, since descriptions for these causes could be diverse and may require greater specification and precision in the descriptive text for a suitable processing.

Maximizing the Use of South African Administrative Information Systems in Undertaking Limited Automatic Coding of Causes of Death

Sulaiman Bah, Statistics South Africa (StatSA) and Theo Ireton, Private IT consultant, South Africa

Introduction

Statistics South Africa's (Stat SA) first exposure to the whole idea of automatic coding of causes of death came about, indirectly, through the proceedings of the first ICE meeting in 1996 and, directly, through participation at the second ICE meetings in 1999. It was clear in both instances that the US automatic coding system almost served as the gold standard for automatic coding of causes of death. Stats SA's initial idea was naturally to make use of the US coding system. It was soon realized that this was not going to be an easy task.

One reason for this is the bilinguality of medical certification of deaths in South Africa. Physicians use either English or Afrikaans in completing death notification forms. The issue of language conversion poses a challenge in the use of the U.S. coding system. In the 1996 ICE meeting, Jim Hart, who was then the lead programmer for SuperMICAR, gave a detailed presentation on the technical aspects of language conversion. In the presentation, he showed how SuperMICAR could be converted to handle non-American English spellings such as British English. He argued that the solution (via changing the word dictionary and adding words to the lexicon) would work for most Germanic languages of Europe and perhaps even the Romance ones. Jim Hart warned that if direct translation (as in French/English medical terms) was not possible, then there was little possibility that SuperMICAR could be translated to that language at all. The reason he gave was that complete translation would require the following:

Conversion of the MICAR dictionary
Conversion of the Words dictionary
Conversion of the Lexicon
Conversion of the Drop Words, Synonyms, and other associated tables
Translation of the External Cause Prompt coder
Translation of over 600 word-specific exceptions
Complete translation of the code

This is a mammoth undertaking as it basically means starting from the beginning as the U.S. programmers did. For many countries, this option of rewriting the whole system is not practically viable. In the case of South Africa, as Afrikaans has got a Dutch origin, the direct translation approach could work. For example, the Afrikaans expression for advanced liver cancer is *gevorderde lewer kanker*. Each of the words in the expression can be linked to its English equivalent. This was going to be the logical route to follow, if the data for the full causes of death was being sent to the national statistical office in electronic form. As this is not the case, another option for handling the language issue was considered.

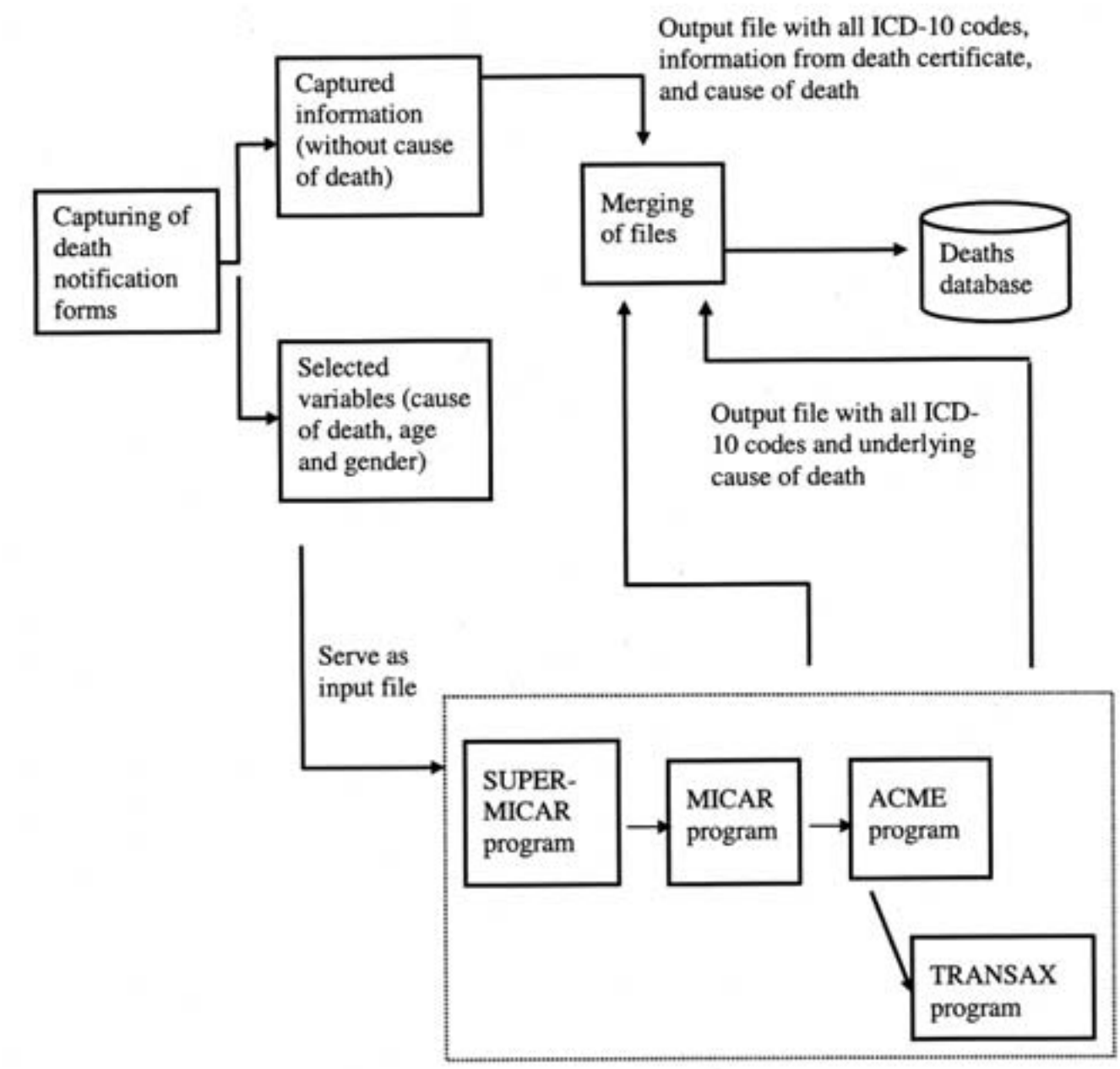
The other reason for the perceived difficulty is the institutional IT restriction. Stats SA had standardized on Visual Basic (VB) as its data capturing program, and programmers were urged to use it in developing computer systems. Based on these constraints, Stats SA developed a vision for implementing automatic coding of causes of death (old vision). As the vision was slowly being pursued, Stats SA was urgently commissioned, in 2002, to produce statistics on causes of death for 5 years, 1997–2001, based on a sample of registered deaths. This project (the Causes-of-Death Data Capture Project) was started and completed during 2002. Whilst the project informed policy makers on the trends in the leading causes of death, it proved very beneficial in uncovering the importance of other administrative data sources, primarily, the South African Population Register (SAPR). The SAPR captures demographic and other details of South African citizens and residents who had applied for, and obtained, identity documents. For deaths, the date of death, place of death, and the immediate cause of death (the first listed cause) are added to the details already on the population register. In the past, exploitation of the cause-of-death data from the population register was dismissed on the

grounds that they could not yield underlying-cause-of-death statistics. However, as a result of this project, insights were gained on the relationship between the immediate and the underlying cause of death and about the number of multiple causes of death filled in on death notification forms in general. These insights led to another vision for the automatic coding of causes of death (new vision) that is based on exploiting the population register and other related administrative information systems. In the sections following, the old and new visions are outlined as well as the insights gained from the Causes-of-Death Capture Project. The preliminary findings are discussed and the way forward is outlined.

The old vision

Recall that in the full U.S. coding system, the literal text of multiple causes of death serve as input into SuperMICAR. This produces ''sanitized'' text descriptions of the causes of death, and this serves as an input into MICAR. The output from MICAR serves as an input into both ACME (to produce underlying-causes-of-death statistics) and TRANSAX (for producing multiple-causes-of-death statistics). Since Stats SA was going to retain its data capturing program in VB, the old vision was that the basic capturing was to be done using VB; thereafter, the data required for input into the U.S. coding system were to be extracted from the database and fed into the U.S. coding system. The output from the system, in terms of multiple causes of death and underlying cause of death, are merged with the remaining dataset (containing socioeconomic variables) to produce the full deaths database. Under this system, the non-cause-of-death section of the VB program will include look-up tables for place names, occupation and industry, thereby reducing errors and time in capturing these variables. This plan is schematically shown in Figure 1. On the language issue, considering that the cause-of-death capturing was to be done at the national statistical office, one option that was considered was to build a new dictionary (of causes of death) relating causes of death in Afrikaans to English. In that way, the data capturer can enter the cause of death in Afrikaans, as stated, and it will programmatically be changed to the English equivalent before being fed into the U.S. coding system. The alternative to this is to convert the MICAR dictionary into Afrikaans and process Afrikaans forms separately. In a dual-language environment, this would not be too practical. As such, the afore-mentioned option of building an Afrikaans-English dictionary was settled upon. This dictionary was slowly being built by the programmer, as time allowed, until early 2002, when all work had to be interrupted to attend to the commissioned project on causes of death.

Figure 1. Stats SA's Envisaged Strategy for Implementing Automatic Coding of Causes of Death (Old Vision)



The 2002 Causes-of-Death Project and insights gained

As South Africa's HIV/AIDS problem was growing, there was pressing demand for timely statistics on causes of death to help understand the magnitude of the problem. By 2002, Stats SA was still on manual coding of causes of death (with look-up tables in its data capturing program) and its latest report was for 1996. The request was then put forward that Stats SA should process all the outstanding causes of death statistics from 1997 to 2001 to help show trends in leading causes of death. The strategy decided upon was to draw a

15 percent sample of all registered deaths between 1997 and 2001 and process them fully. As the manual coding of all the death notification forms was going to very challenging, it was decided to revisit the idea of automatic coding of causes of death as outlined in the old vision. The status of progress made on the plan to implement automatic coding was then assessed. The findings were that unnatural deaths that cannot be coded by the automatic coding system accounted for about 20 percent of deaths (at about 1997 but reduced markedly afterwards) and would need manual coding. Also, about 50 percent of certificates were completed in Afrikaans, which was significant and made the Afrikaans-English dictionary an important component of the automation project. However, because of the shortage of staff and the pressure of work, not much progress had been made on the Afrikaans-English dictionary. Lastly, the data capturers typing in the causes of death from the death notification forms needed to be trained in medical terms. For all these reasons, it was decided against using the old vision for processing the causes of death data for the project. At the end, manual coding of multiple causes of death was done together with manual selection of underlying causes of death.

The study of multiple causes of death carried out during the Causes-of-Death Project helped shed light on three important areas: a) the average number of causes listed on the death notification forms; b) the number of causes of death forming the basis for the selection of the underlying cause of death; and c) the relationship between the first listed cause of death (the immediate cause) and the underlying cause of death. Firstly, the data showed that for each year, the ratio of the number of multiple causes to that of the underlying cause is higher for females than males. The average ratio for males is 1.58 and that for females is 1.66. Secondly, the data showed that, on the average, in 72.2 percent of the male deaths, the first listed cause of death (the immediate cause) is the same as the underlying cause of death. For females, the corresponding average figure is 68.8 percent. For males, with the exception of 1997, this percentage has remained fairly stable, ranging between 70.0 percent and 73.0 percent over the remaining years of the study period. For females, with the exception of 1999, this percentage has remained fairly stable, ranging between 68.0 percent and 71.0 percent over the remaining years of the study period. Lastly, the data showed that on average, for males, 59.9 percent of the underlying causes of death were chosen based on only one listed cause of death (which could be anywhere on the certificate), 26.3 percent were chosen based on two causes of death, and 10.3 percent were chosen based on three causes of death. Over the years, the percentages underlying causes of death based on one, two, or three causes of death do not differ much from the average. For females, 53.9 percent of the underlying causes of death were chosen based on only one listed cause of death, 30.2 percent were chosen based on two causes of death, and 11.8 percent were chosen based on three causes of death. Over the years, the percentages underlying causes of death based on one cause of death do not differ much from the average (with the exception of 2001), and the percentages of underlying causes of death based on two or three causes of death do not differ much from the average over the study period. These findings mean the following:

- Multiple cause-of-death reporting is fairly low in South Africa as physicians only report less than two causes of death, on the average.
- Partly as a result of the low reporting of multiple causes of death, the immediate cause of death often times corresponds to the underlying cause of death.

This means that the population register data can be used for automatic coding of causes of death and would yield underlying causes of death data provided it can be verified that the death notification form indeed had only one cause of death stated. For this verification to take place, other administrative information systems have to be made use of.

The archiving of death notification forms and related information systems

As in other developed countries, death notification forms go through the two stages of registration and archiving. The registration of deaths (for South African citizens and residents) essentially means entering the limited details of the deceased onto the population register. Thereafter, the death notification forms are sent for archiving. At this stage, a bar code sticker is affixed on the death notification form and then put on microfilm.

Once this has been successfully done, an indexing system is used to capture the ID number of the deceased, the microfilm roll number and its position on the microfilm (frame number). A service provider (Zytek) maintains this indexing system on behalf of the Department of Home Affairs. The death notification forms cannot be released to Stats SA until they have been verified against their images. This was what led to the huge bottleneck and caused a slowdown in processing cause- of-death statistics from the hard copies. The good part is that the rolls of microfilm can be released for copying, if required. So, during the course of the 2002 Causes-of-Death Project, Stats SA contracted a service provider to collect all the rolls of microfilm for registered deaths between 1997 and 2001, scan the images of the death notification forms, and subsequently print out their images. In this circumventing manner, the project conveniently worked off printed images, rather than the hard-to-get original forms. As a useful by-product, Stats SA acquired the CD equivalent of all the microfilm rolls and paid Zytek for a copy of the indexing database. Since the Zytek index database has the microfilm roll number as one of its parameters while the CDs had numbers, a simple file was developed to link microfilm roll number to CD number. In essence, what can be achieved from these three systems is as follows: an ID number (from the population register) can be entered into the Zytek index database (either interactively or in batch mode) and it can show the microfilm roll number that contains the image of the death notification form and its position on the film. From the microfilm roll number and the position, the CD number can be extracted and the image can be located.

Under these circumstances, the limited automatic coding would have to involve two important stages. The first is to code immediate cause of death written on the population register (for both Afrikaans and English terms) and the second is to use the ID number to locate the image of the form and verify that the form had only one cause of death. If indeed the form had only one cause of death, then the coded cause is the underlying cause and that record is transferred to the full database as having been successfully coded. If the form had more than one cause of death, it is located and the other causes are manually coded. In the sections below, these two stages are clarified in more detail.

The automatic coding of causes of death from the population register

The automatic coding is done using the thesaurus principle, and the program for doing that was written in VB and called the THES Coder. The thesaurus used by the THES Coder was made up of all the frequently mentioned causes of death, plus the different variants in their spellings in both English and Afrikaans. Commonly used abbreviations of causes of death were also included in the thesaurus. The THES Coder was tested and refinements were made based on the results. The algorithm used by the THES Coder is as follows:

- A string consisting of the cause-of-death text (COD), age and sex (from the population register) is passed to the THES Coder System.
- THES Coder searches for an exact match based on all defined variables.
- If a match is found, THES Coder returns the ICD–10 code and exits.
- If a match is not found based on the symbol variables, THES Coder tries to get a code by checking if the passed variable exists within a general symbol. For example, if the passed variable for sex is ‘‘Female’’ and THES Coder cannot find ‘‘Female’’ within a symbol field (a direct match), THES Coder will check if the word ‘‘Female’’ exists within the general sex symbol ‘‘Male/Female’’ and if so, will try to code the text COD based on the general sex symbol and not the passed sex symbol.
- If a match is found, THES Coder returns the ICD–10 code and exits.
- If a match is still not found, THES Coder will try to split up the text COD into several causes. All data that is left over in the text COD that cannot be coded are checked against a standard list of splitter text (i.e., text or symbols which split a sentence, e.g., with, or, ‘‘;’’, etc.).
- If all the splitter text is taken out, THES Coder will code the separated causes found within the text COD and then try to code them into a single underlying cause by using the ICD–10 Ruleset file which accompanies the ICD–10 Thesaurus file.

- If the splitter text still remains (even after text parsing/checking), THES Coder will exit with an error message describing the error and including all the variables passed to it.
- If a match is found, THES Coder returns the ICD–10 code and exits.

The verification stage and the linkage between the THES Coder and the other systems

Since THES Coder uses only one line input of causes of death from the population register, there can be more than one completed line (up to five and sometimes even more). A basic requirement for THES Coder to work would be a verification system in which it would be confirmed that a particular certificate indeed has only one line (in which case no further coding is required) or more than one line (in which case, manual coding would be required). Figure 2 shows a flow chart of the essential steps involved. There are two options for this verification process: preverification (prior to getting the output of the THES Coder) and post verification (after running THES Coder). Both have their advantages and disadvantages. For the manual coding to be done, physical extraction of the form is needed, but for the verification, an electronic search can suffice. For the physical extraction to be done, there is need for a simple tracking system that links ID numbers, microfilm number and the physical location on the shelves in the storeroom. This tracking system is actually used primarily as a cataloguing system to enable forms to be easily taken out, coded and returned to the shelves. The tracking system helps to locate the physical position of a death certificate on a shelf. For a certificate with ID number, it uses the microfilm number and the year of death as the indexing numbers, together with the position number on the shelf. For certificates without ID numbers, it uses a combination of identifying characteristics (serial number, date of birth and death of death) to yield a kind of unique identifier for the certificate.

The linkage between all these systems is shown in Figure 3. The file used for the tracking system is called the locator file. Both this file and the extracted data from the population register serve as inputs into the THES Coder system. For successful matches, the first output from the system reflects the inputs (cause-of-death text, age, and sex), the ICD–10 code, the locator details (roll number, frame number, CD number and position on the shelf), and a ''Yes/No'' field for post-verification.

Preliminary findings

The preliminary findings have been promising. The THES Coder successfully produced an output with all the necessary locator details. These details were used to do postverification (that there was indeed only one cause of death stated). Unfortunately the project had to be interrupted. The reasons are many, partly dealing with lack of sufficient buy-in by some staff members, staff turnover, financial constraints and some kind of breakdown in authority.

Figure 2. Flowchart of the Essential Steps Involved in Undertaking Limited Automatic Coding of Causes of Death

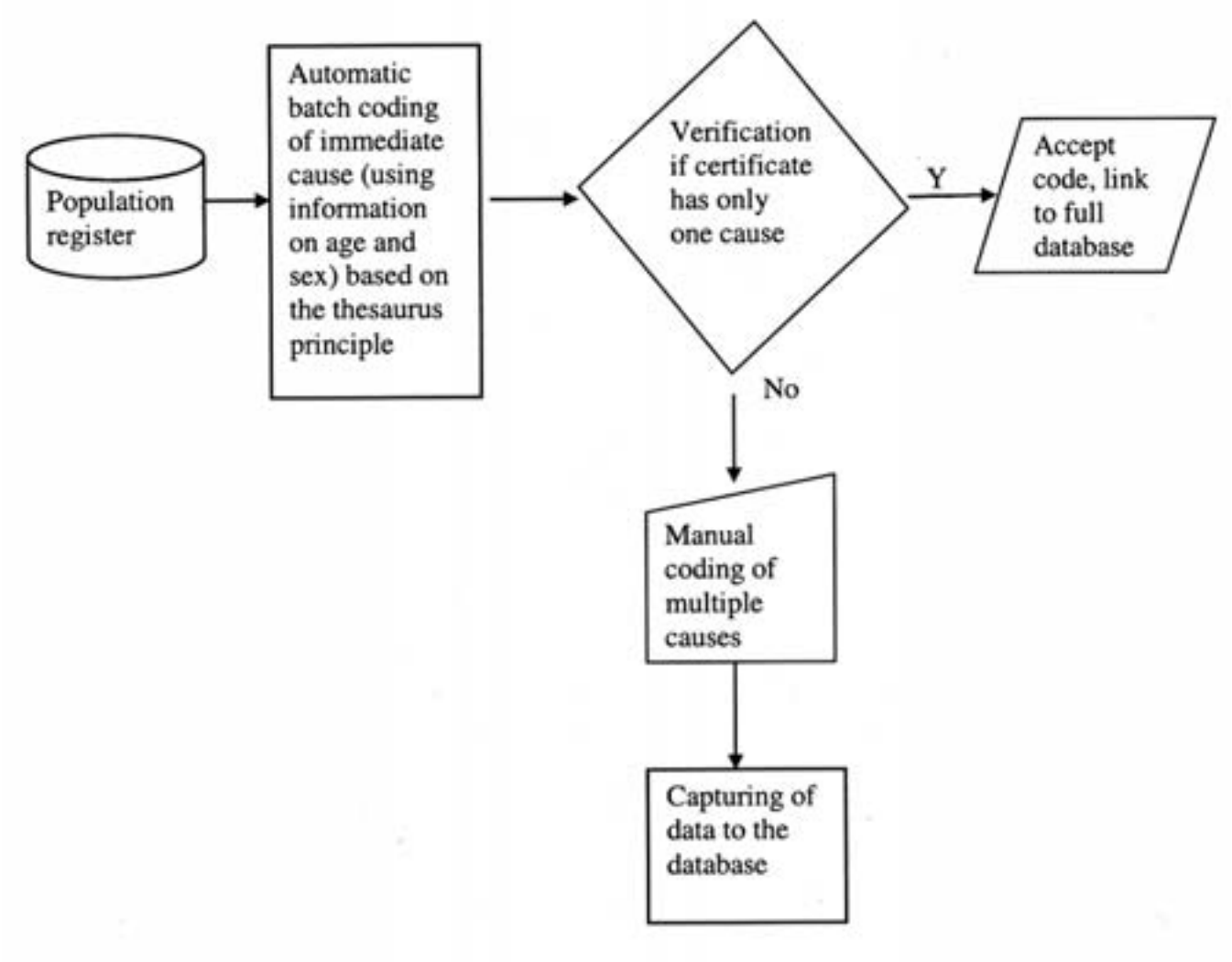
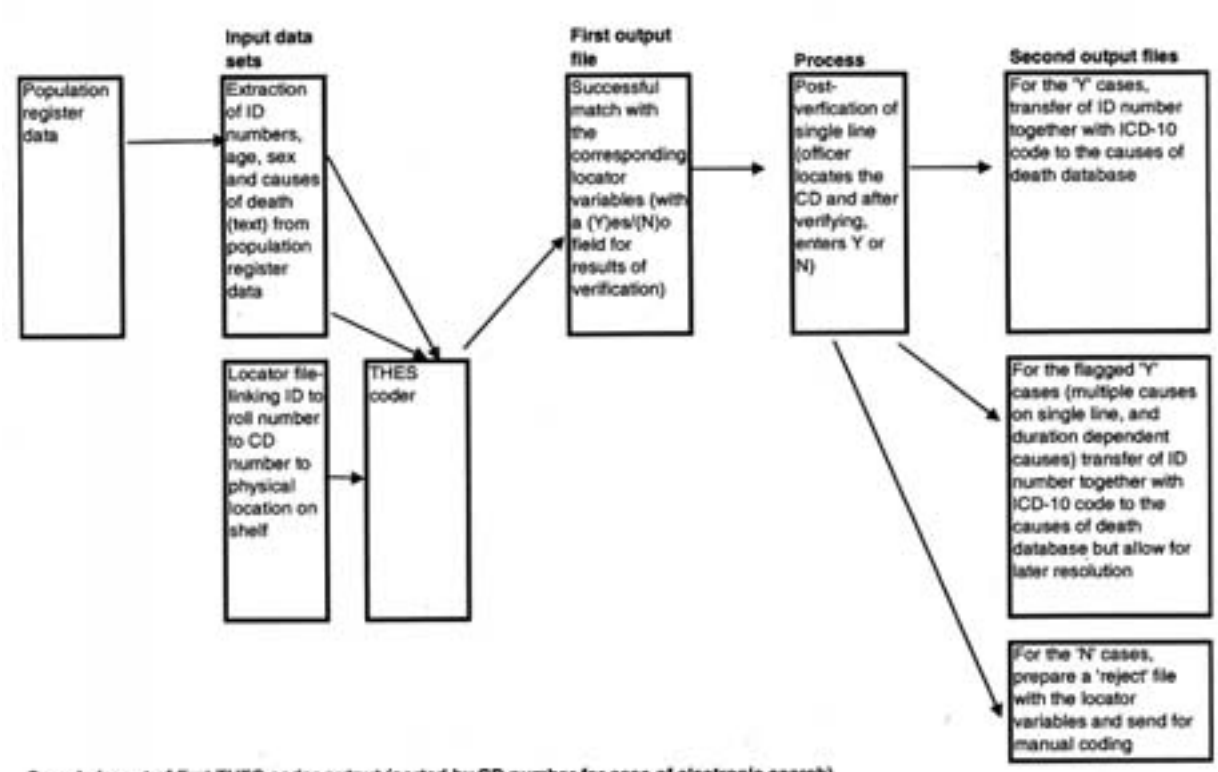


Figure 3. Linkages between the THES coder and other systems



Sample layout of first THES coder output (sorted by CD number for ease of electronic search)

ID no.	Causes of death (text)	ICD-10 code	Roll no.	Frame no.	CD no.	position no. on shelf	Indeed single line?Y/N [blank]

Sample layout of second THES coder output (sorted by roll no. and shelf no. for ease of physical search)

ID no.	Causes of death (text)	ICD-10 code	Roll no.	Frame no.	CD no.	position no. on shelf	Indeed single line?Y/N [filled in]

Way forward and conclusion

One crucial factor in the use of full automatic coding software is the basic availability of information on multiple causes of death. Where medical certification of deaths is relatively poor and the number of causes of death listed on the death notification forms are, on the average, less than two, a simplified form of automation could be considered. The simplified system described here has two basic uses. In the first case, it could be used to code the immediate cause of death from the population register and that can be used to produce an ''Advance Release of Recorded Causes of Death.'' This will be a very timely report and can help give quick statistics on the trends in the leading cause of death. In the report, it can then be explained that in the South African context, the immediate cause of death was the same as the underlying cause of death in x percent of the cases. In this case, all the verification process and the locator details would not be necessary. In the second case, it could be used to speed the coding of causes of death in full death notification forms. In this second use, all the forms that indeed have one cause of death would be coded automatically and transferred into the database. Only those with multiple causes of death will be manually coded. But in the South African context, these are not many at present.

For the near future, the full automatic coding of causes of death should be considered, paying very close attention to the interface with the system used by the Department of Home Affairs. Currently (as at 2003), the Department of Home Affairs is migrating its document-storage system to the Computer Assisted Microfilm (CAM) technology. Once this technology is fully operational, then Stats SA will no longer need to collect rolls of microfilms for scanning. The scanned images of the death notification forms will form the electronic output to which Stats SA would have access. With the help of ICR (Intelligent Character Recognition) technology (already in use at Stats SA during the census of 2001), the image of the handwritten causes of death can be converted into proper words, which would then be fed into the U.S. coding system for automatic coding. In this case, however, for the purpose of handling the Afrikaans aspect, Stats SA would have to resort to the option suggested by Jim Hart for updating the dictionary and adding words to the thesaurus. The technology is in place and the know-how is there as well. The will and drive are what is needed to help bring it to reality.

Future Directions of the NCHS MMDS Software Suite

Ed Elliott, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

I am one of the programmers who work with Donna Glenn at NCHS to develop the MMDS software suite. What I am going to talk about is the current state of the software, how it is put together, and where we would like to see it go in the future.

It sounds like most of you are aware of the three main applications from listening to these other presentations: we have SuperMICAR for data entry, MICAR 200 to automate the multiple-cause coding, and then ACME TRANSAX to determine the underlying cause. Each of these applications is pretty much self-contained; they all have graphical user interface; they have the processing code, the interface with Look-Up Tables, Decision Tables external to the program; and they have to be installed on a user's machine in its entirety. It is a self-contained unit. It is propagated throughout an enterprise of all the users of the software; that leads to some weaknesses that are within the system because we could get different versions of the software on different machines, which would dilute the integrity of our data.

The software started off on the mainframe; then it got ported or converted to the DOS environment and was converted to Windows a few years ago. The main language used for the processing part of the application is the C language, and you can pretty much consider that to be a black box for each of the three applications. We as programmers do not really like to get in there and tinker around with it too much. The graphical user interface is done in C++, which is more object-oriented and easier to maintain. However, we have the dilemma of what to do with the processing code to move forward, especially as we consider going to Web-type applications.

Also, we do not really have any standard data format for the various files used. We typically store the data in the database file format (DBF); we have ASCII text input files; and some of the Decision Tables are still in hash table format, which is really proprietary to us. The different formats could be a weakness for moving forward. We would like to standardize.

Figure 1 shows the layout of the current ACME program. The version numbers are across the top. I have ACME Version 1.0, and then on down the Line I have ACME Version 1.3 or 1.4. We have users with different versions of the program, which are not entirely comparable because the processing rules have changed with each new release or update. Therefore, people with different versions will not get exactly the same results. Also, along the bottom row, the Look-Up Tables or Decision Tables could also differ in version if they are not installed properly on the user's machine.

We would like to update the actual processing code, that is, pretty much pluck it out of each of the three applications and put it in a self-contained module that could easily be linked into other programs that either we develop or that would have widely-published methods that any of you could use to integrate into them, especially with the ACME program. We would package it into an object called the DLL or Dynamic Link Library (Figure 2). Later on when we start moving towards more Web-based applications, we could wrap that DLL into an XML Web service—which is pretty much the darling of the current software development world—and that could be accessed through different means such as JAVA applications or dot.net applications. One could develop multiple clients to interface that same processing engine.

Figure 1.

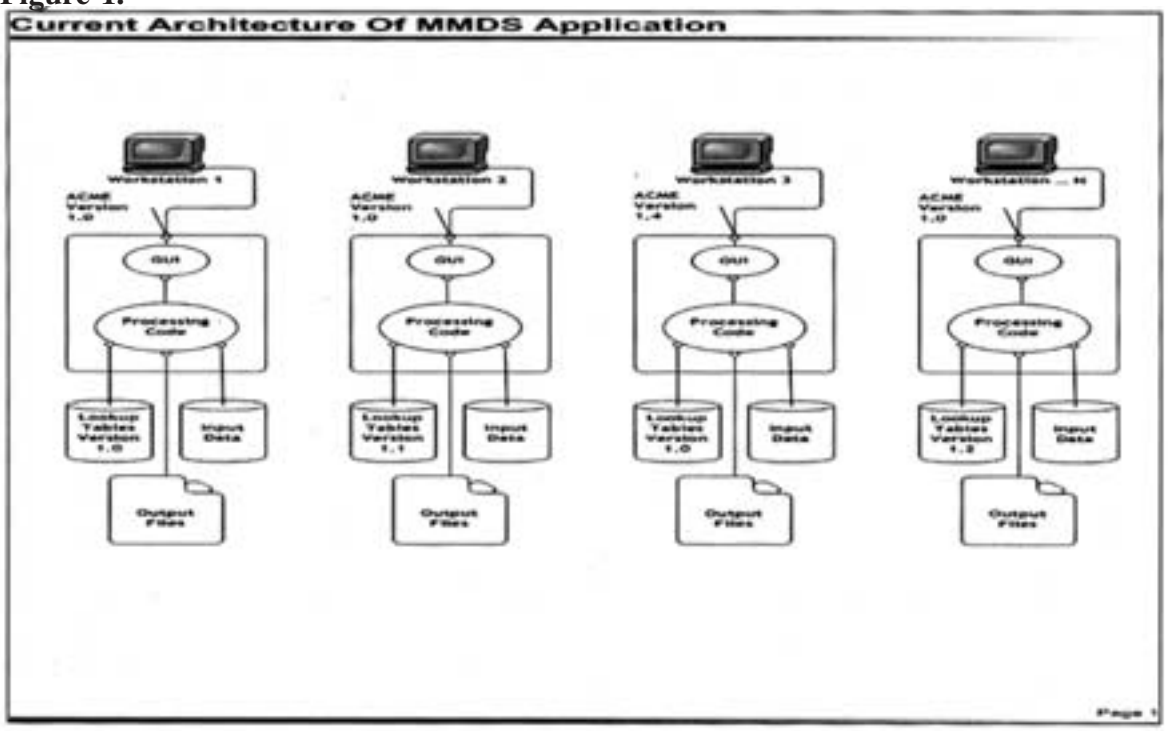
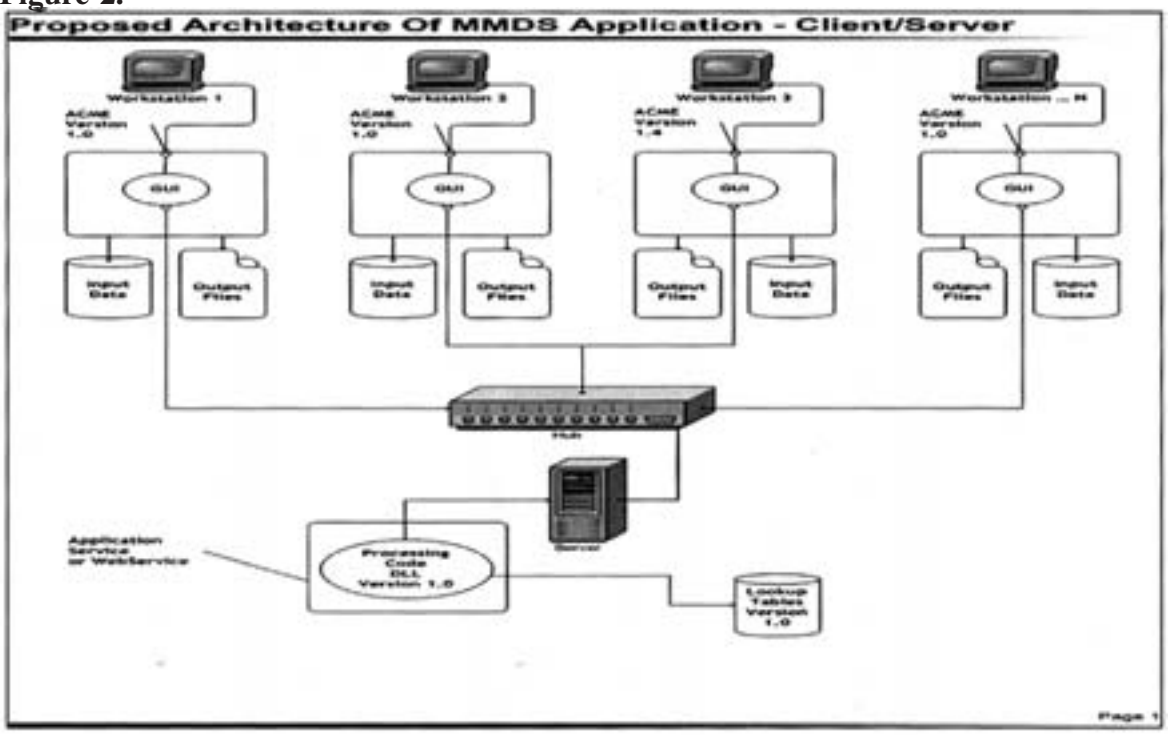


Figure 2.

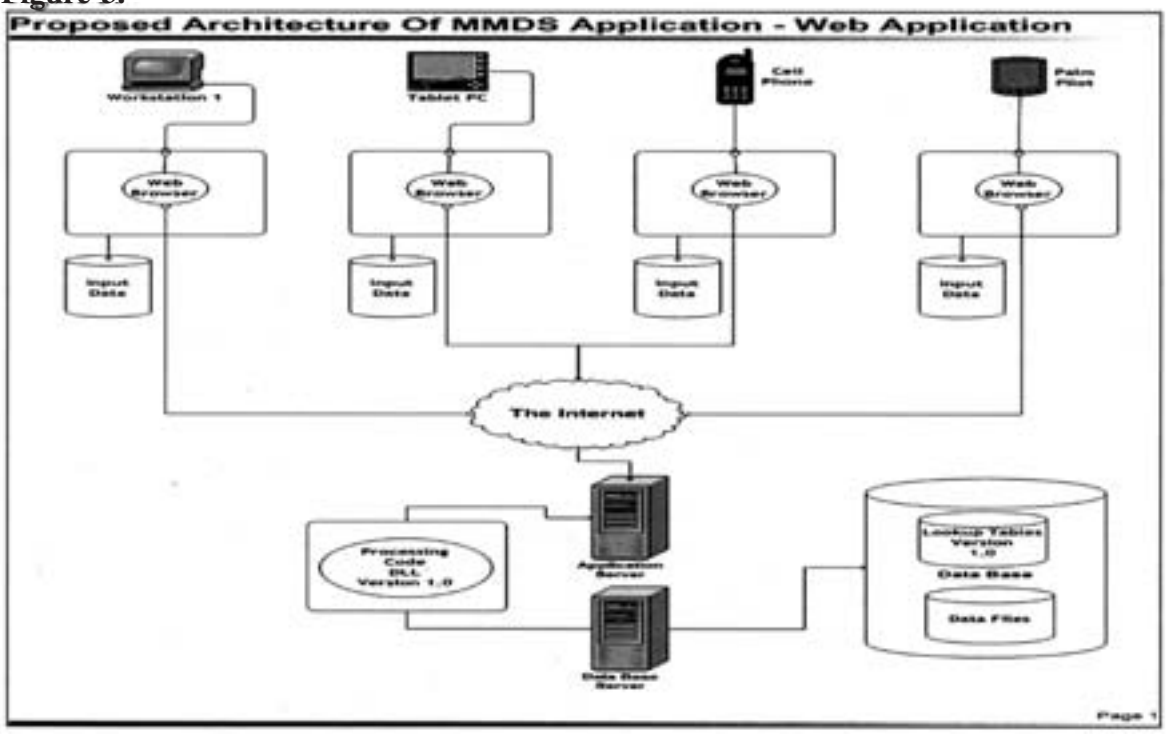


We would also like to standardize the data format for input and output files; XML is the current standard so that would be desirable. It would also be good to disengage from the Fox Pro file format for the data files because we have had corruption problems with those files in the past. Consequently, these changes would result in a more robust database for data storage.

We would probably move forward in a phased approach: once we got this DLL module working, we could develop a client server application where we extracted or used the extracted processing code, which would reside on the server along with its set of Look-Up or Decision Tables (Figure 3). Then our client applications would go through a server for access. The client applications could still differ in version number, but there would not be as many problems because various clients would differ mainly on fields on the form or something like that. While it might not work, at least it would not degrade user data as much as the current setup.

Once we had this approach working, we could have multiple different clients. Nationally, we would have the current Windows client, much like it is. We would also have Web-based clients, which would be the ideal method because then we would totally have the whole application—including all the look-up tables—residing at a standard place that could be accessed through a Web browser. This would alleviate a lot of the installation problems. We could also develop a batch processing mode of operation where you could just pass a file in through some FTP side and it would just fit right through the file and give you results. In addition, there are new mobile devices, palm pilots, PDAs, tablet PCs, and cell phones for which applications could be developed.

Figure 3.



Ideally, we would get to the whole Web-based situation where everything resided on one end, was all one unit, and there would be a single version that could be accessed through a Web browser with your input residing on the client end. It could be accessed through multiple different means as I show across the top of Figure 3. We would start with ACME because it is pretty much the world standard; it is language-neutral, so there are not some of the language-related issues that MICAR 200 and SuperMICAR have. MICAR 200 is a little bit less intensive on the processing side than SuperMICAR, but SuperMICAR interacts with the actual data entry form a lot more, so that would be next. And then eventually MICAR would be addressed.

The proposed changes would have a lot of benefits, especially once we got to the whole ''boiler base'' solution for the U.S. State users, because a lot of times we ship out a new update to the States and they may or may not install it, at least not right away. We have means for detecting what version they are using from the data files that they send back to us, but our changes would alleviate some of those problems. For international users, taking the processing code out of each of the individual applications would result in your having three building blocks to develop your own solutions.

Caveats involved in making these changes are resource limitations. We are getting better at the actual processing of the data, so I think we may get to the point where we can take the time to make some improvements. We are also training the existing development staff in these new technologies.

In closing, modularizing the software and separating the actual processing, that is, the core of the application from the presentation on the form, can be beneficial to everyone.

Thank you very much.

Discussion on Presentations of Session 1

D. GLENN: We have about 15–20 minutes left for questions. You can address your question to anyone. Please state your name and the country you are from. Questions?

L. GERAN: Leslie Geran from Canada. I have a question for those countries that are using optical character recognition, particularly Sweden. I ask this because Canada has had an uneven history of using optical character recognition (OCR), that is, we have found that it works really well for very large locations like our national census but for smaller applications—like in surveys—it is too much trouble and too expensive. Given that Lars Age said he had 55 percent handwritten death certificates, I was wondering whether he sees a more long-term use of those optical character recognition systems.

L.A. JOHANSSON: The OCR systems are getting better and better, and we use them not just for text; we use them for taking values from the check boxes into our files. As I said, it is not automatic. People working in this field say that in just a few years those systems will be able to interpret handwriting.

PARTICIPANT: Doctors' handwriting?

L.A. JOHANSSON: I think that would possibly take four years more. But I think there is a future in it, absolutely. The ability of OCR to sort out things that were entered to the form from parts of the form itself has increased incredibly, so yes, I think this is very possible.

C. ROONEY: Cleo Rooney from the U.K. I wanted to ask what are the Japanese rules that are applied? Are they different from the standard ICD–10 rules?

M. KIMURA: Basically these are ICD–10 rules. However, because of our culture, the percentage of heart failure has been like 30 to 40 percent but it does not mean that all of them died of heart failure. So, we modified the rule to prevent unnecessary fake heart failure deaths.

J.A.O. GARCIA: I would like to have a clarification from Lars. He said his system does not use ERN codes. I do not know if I misunderstood.

L.A. JOHANSSON: No, that is quite right; we do not use the Entity Reference Numbers. In the session on language tomorrow, I will try to explain in more detail what we did instead.

S. WALKER: I am Sue Walker from Australia. My question is to the gentleman from South Africa. You say that about 70 or so percent of your death certificates have only one cause. Can you tell us what is the burden of external causes and how you handle those? Do you have a report of the nature of injury and of the external cause? Or one or the other? Or neither?

S. BAH: Thank you. In South Africa, the Births and Deaths Registration Act was modified not to allow the underlying cause of death. When there is an external cause, the physician is just free to write the external cause, so we have a lot of unspecified external causes of death.

A. MININO: Good morning, my name is Ari Miniño from the National Center for Health Statistics, and I have a question for Gérard Pavillon. I was very impressed by the fact that STYX gives feedback, and it explains what it is doing and how it gets to those decisions for coding, etc. I was wondering whether you could expand a little on that, and especially I want to know whether it was very difficult to implement this feature on your program.

G. PAVILLON: Yes, at the beginning I would just want everyone to be clear. For each step, I mean that for each ICD rule that was applied or not, I gave the name of the ICD rule and then why it was applied or not. At the end you have the rule sequence and, for each rule, the conditions that the system applies to use the rules or not. For complex death certificates where you have a lot of rules applied, it is really interesting to know how you get the underlying cause, and for the coders it is important.

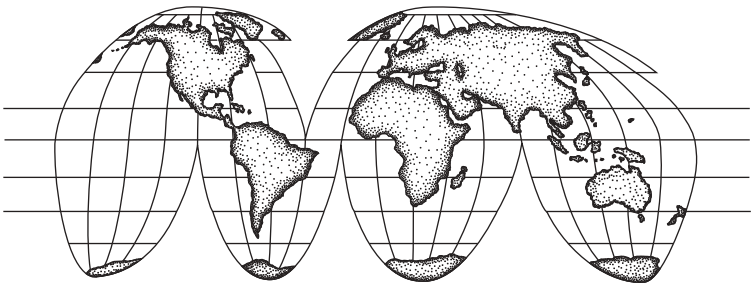
PARTICIPANT: I come from the National Board of Health in Denmark, and I would like first to thank all the presenters for these very interesting and educating presentations. They put a lot of questions in my head, but I was actually focused on one for Edward Elliott. Denmark is currently reorganizing our statistical system, and we would like to integrate the automated code to the system itself. Will the revision you explained and showed us give this possibility? And could you say more about the time horizon?

E. ELLIOTT: Thank you. Yes, it will open up the actual core of each of the programs to external input from whatever program you want to use as a front end. If we can get SuperMICAR modified as I described, you could have your own form with your own language on the form, but the changes would allow input into, for example, ACME, and you could just pass in records and get the processed output out the other end. We have recent requests for modifying the existing program to allow this, so we would have to start by way of filing things in ACME not .exe format and then we would modify ACME so you can pass in a string of words indicating what the file name of the label was rather than going through the menu system and selecting the file to be processed. Thus, there would be some sort of match process feeding the data files. By separating the actual processing code from the main application, you would have more access to doing things like that. Timeline. Actually, I have a laptop; I am going to be working on that program this week, so I am hoping to get something going by maybe the third quarter of the year to have that part at least out where we can start testing and adjusting it. It is going to take some time to do this.

S. NOTZON: We have people from many different countries, between 25 and 30. For those of you whose native language is not English, I was really impressed with the quality of the presentations this morning. I know that when I have to make presentations in another language it is hard work, so congratulations to all the speakers.

SESSION 2

Multiple Cause



Welcome (Afternoon Session)

Dr. William Steiger, U.S. Department of Health and Human Services

DR. SAM NOTZON: I would like to introduce Dr. Bill Steiger, who serves as special advisor on international affairs to the Secretary of Health and Human Services Tommy Thompson. Dr. Steiger has been involved in a number of activities including negotiations surrounding establishment of the global fund to fight HIV/AIDS, tuberculosis, and malaria. Previously, Dr. Steiger served as a special advisor to Tommy Thompson, then Governor of Wisconsin. Dr. Steiger has a Ph.D. in Latin American Studies from the University of California, Los Angeles, and has lived and worked on three continents: Asia, Africa, and Latin America.

DR. STEIGER: Thank you for allowing me to address you on behalf of Secretary Thompson, who sends his regards and wants you to know what a privilege it is for the Department and for the National Center for Health Statistics, in particular, to welcome you to Washington. He would also like you to know how important we think your work and this conference are to not just the international advancement of automation on mortality statistics but also the work in a number of areas at our Department.

Secretary Thompson really responds well to the presentation of good data and relies on good statistics to make decisions, as do all of us do at the Department. This kind of a meeting is exactly the kind of forum that he likes to encourage as a way of putting an emphasis on international collaboration toward better gathering and better display of data. The large number of countries that are participating in this gathering is indicative of a wide and growing interest in automated coding systems for mortality data. I would like to welcome all of our partners around the world, particularly to those of you from the countries of Central and Eastern Europe, who are about to join the European Union and are interested in harmonizing mortality data with other countries. I send a special welcome to those of you from Estonia, Hungary, Latvia, Lithuania, and Slovenia.

This ICE on Automation is a great example of international collaboration among countries. We are proud in the Department of Health and Human Services to be a leader in that collaboration, along with England, France, and Sweden. We have worked collaboratively on the development of Decision Tables for ICD–10, an essential part of an automated coding system. We have worked with a number of international organizations through the ICE group, including the World Health Organization, EuroStat, the U.N. Statistics Division, and the World Bank.

We have closely collaborated with WHO on automated systems, statistics, and evidence for policy in general. The Secretary is the U.S. representative to the WHO Executive Board. I fill in for him in that role sometimes, and most recently I met the incoming Director General of the WHO, Dr. J.W. Lee of South Korea, who will take over in July. Dr. Lee is focused on data, automation, and information technology as key drivers for his agenda at WHO. You should feel comfortable with the leadership of the World Health Organization over the next five or ten years. He invited a small group of 20 or 25 people to think through some issues with him about the future of WHO. He emphasized his vision for information technology at Headquarters, at the regional and country offices, and then for working with collaborative partners like the ICE and others to provide better data for decision making at WHO.

You know that WHO has responsibility for ICD–10. While it has devolved some responsibility to the collaborating centers, the ICE on Automation is an example of further delegation to countries with technical expertise. Dr. Lee clearly believes that the Secretariat at WHO and the regional and country offices have an important role to play in the work that you are doing. I encourage you in your interaction with WHO to obtain Dr. Lee's manifesto, as he calls it, his vision for WHO, and talk with him and his staff about automation, data, and information technology. You will find Dr. Lee to be a strong supporter of the ICE.

I just want to emphasize how supportive we are at the Department for the National Center for Health Statistics and its continued involvement in the ICE. We rely on the NCHS. For example, we called on Dr. Sondik recently when the Treasury Department approached us about setting up some criteria for the new Millennium Challenge Account. President Bush has set aside a doubling of our foreign-assistance money for targeted grants that will go to certain countries that meet criteria, one of which is ''investment in people'' as

measured by investment of domestic resources in health and education. The Treasury and State Departments were also interested in measuring success. It would be impossible for us to do either without the collaboration of the National Center for Health Statistics. In terms of measuring success of reduced mortality for the major diseases, it is impossible without the work that you are doing, so we owe you a great debt of gratitude.

Again, we welcome you to Washington, encourage you in your important work this week, and thank the organizers and all the funding agencies. So on behalf of the Secretary, I wish you a successful week and thank you for your hard efforts.

Session 2: Multiple Cause

Dr. Cleone Rooney (moderator), Office for National Statistics (ONS), England and Wales

I am pleased to chair a session on multiple-cause-of-death coding and analysis. For years, there have been recommendations about coding all the conditions on the death certificate and about how to analyze them. Since ICD–6, almost no country routinely codes all of the conditions on the certificate and publishes statistics based on them. With automation we have an opportunity to do the coding, but there are still a lot of issues to be addressed.

We have some varied presentations this afternoon. Roberto Becker from PAHO and Ruy Laurenti from the Brazilian WHO Center are going to talk about some issues in coding multiple causes of death and the need for internationally agreed definitions and standards. Then, Augusto Hasiak Santo from Brazil will show us some comparisons of underlying-cause and multiple-cause data on diabetes from a range of countries and talk about how multiple-cause data can help us understand differences in underlying-cause statistics. Finally, Eric Stallard from Duke University will show us a rather innovative way of looking at multiple-cause data using the outputs of the automated system in the United States.

Multiple-Cause Mortality Coding

Dr. Roberto Bécker, Pan American Health Organization (PAHO), Washington D.C., U.S.

There are differences in the perspective of using underlying-cause and multiple-cause data. With underlying cause, basically we are discussing prevention. However, there are known limitations of using only underlying cause: the epidemiological principle of multicausality disappears. Further, the underlying cause may not be the originating antecedent cause, for example when we change or modify the first selected cause. Maybe the underlying cause is different from what the physician intended to say or stated as the beginning of the process. In addition, we may have different selections and codes from different coders, and there are many hidden conditions such as nutrition problems, malnutrition, obesity, hypertension, diabetes, alcoholism, and so forth. There are also some arbitrary definitions, especially related to precedence. We have to make assumptions that may not be correct all the time. And it is very difficult to select one underlying cause with very mixed conditions in chronic degenerative diseases.

With multiple causes, we may have solutions for many of the problems that result from using a single underlying cause. Thus, we can identify complications using the multiple-cause sequence, which we cannot do working only with underlying cause. We can restore the natural history of the diseases, which also is lost with a single cause. We can get more information on the prevalence of health problems. I am not saying that with multiple-cause we will know the prevalence of the problem but we will get more information on the prevalence of health problems. We can study the relationship between external causes and injuries. We can identify and make interventions on risk factors if we put this information in our systems. We can work with etiology and clinical manifestations, including the well-known but not that often used double-coding or ''dagger-asterisk'' system. Also, in perinatal mortality, we can better analyze maternal and child factors.

We do need international standards for coding multiple causes of death. In spite of our current use of four instead of three lines on the death certificate, there still may not be enough space to provide an incentive to the certifiers to give us more information. Maybe we need new instructions to complete the death certificate because we used to instruct ''do not put more than one diagnosis per line.'' Thus, to get more information we may have to review this instruction.

The multiple-cause tabulations are complex; they depend on the type of analysis we want: mention, number of mentions, underlying, terminal, intermediate, etc. We may need important changes in the software; for example, the U.S. system may have to be adapted if we get international standards for linked codes. We will need training materials and trained coders. We have to pay attention that some conditions may increase because of several mentions on the death certificate of similar conditions.

Where can we get data for analysis of multiple causes? We can get it from databases, for example, generated by TRANSAX in the databases of the U.S. We may be able to complement this directly from samples of death certificates with such non-processed variables as timing between conditions and ill-defined conditions that are not very often found in mortality databases. We can also look for more information in medical records including lab results, treatment, procedures, and so on. Probably the most complex and complete way is to perform verbal autopsies, redoing completely the medical history. For any of these sources the coding rules and principles should be the same, regardless of the source of our data. We will need definitions for other types of causes in addition to underlying cause.

In multiple-cause coding, the first rule is the correct and standard selection of the underlying cause of death. Usually the idea is to put an individual code for every diagnostic term, condition, sign or symptom reported on the death certificate. Are all the codes valid for multiple coding? In my opinion, all are, including asterisk codes, postprocedural, and ''Z'' codes in the last chapter of ICD–10. In my opinion, the rules and notes of inclusion and exclusion are valid only for underlying-cause selection, so we have to review whether we need specific inclusion/exclusion notes for multiple coding. Some of them we will need but some maybe not; we have to review all of them.

Another point is related to linkage where we can have different situations in multiple-cause coding. We can have hidden conditions; for example, in a case with hypertensive renal disease plus acute myocardial

infarction, the underlying cause—hypertension—would disappear. However, with multiple-cause coding, we may just put independent codes for each entity. In another situation, linked codes may be used for several associated conditions. For example, in the case of HIV disease plus dementia, B22.0 is the code for HIV disease resulting in encephalopathy, which includes dementia; but it includes several other conditions. If we just use this linked code, we are losing information. The solution could be to use, for example, a specific code, F02.4 , an asterisk code, which is exactly ''dementia in HIV disease'' or simply the general F03 code ''unspecified dementia.''

There are situations where we get very specific codes for a combination of conditions; one example is K57.2, ''diverticular disease of large intestine with perforation and abscess.'' The meaning of this code is unique and explicit so one does not need several codes; all the information is present in a single code.

For maternal mortality, a recommendation from the FIC-Network states that when the underlying cause is selected in Chapter XV (''Pregnancy, Childbirth and the Puerperium''), any associated condition or complication should be coded in other chapters to provide more detailed information. For example, ''postpartum coagulation defects'' is a general statement, but ''fibrinolysis'' is a specific code from another chapter. If the underlying cause is not in Chapter XV, at least one code should be chosen from this chapter. Let us use the example of B24, ''unspecified HIV disease,'' where we can use the code O98.8, ''other maternal infections and parasitic diseases complicating pregnancy, childbirth, and the puerperium,'' because the exclusion note is for the underlying cause. Thus, we will have in the record one code from Chapter XV to identify the maternal mortality.

Another example is an external cause such as consecutive accidents. Imagine flooding causing a car accident, fall in a river, and drowning. In this case, we can code all the external causes and all the injuries.

Another point is related to data consistency. With multiple causes, for all the codes, we can check the consistency of not only underlying cause with sex and age, but also with unlikely or very rare conditions. We can expect repetitions. For example, ''acute bronchitis, unspecified'' is J20.9. The same code would be used whether acute bronchitis were mentioned with bronchospasm or specified as septic. With multiple-cause coding, we can use specific codes for bronchospasm and sepsis to provide more detailed and complete information.

Sometimes certifiers provide considerable information on the death certificates that result in repetitious or very close codes. For example, there is a code for ''junctional premature depolarization'' (I49.2) and on the same death certificate you can get ''cardiac arrhythmia, unspecified'' (I49.9). In this case, I prefer to choose the more specific code. Alike conditions may inflate some cause groups. An example is ''multiple sclerosis'' (G35) and ''acute transverse myelitis'' (G37.3), which are not the same thing but are in the same group in ICD–10: ''Demyelization diseases of the central nervous system'' (G35–G37). Much work needs to be done for this type of situation. We will surely need decision tables for multiple-cause coding that are different from those for underlying-cause coding.

Finally, there are different ways to organize the data depending on what we are going to do with the data, what type of analysis, and the nature of the relationship among the causes. One may simply have underlying cause plus other diagnoses, that is, one field for underlying cause, and several for other causes. In many countries, multiple-cause coding includes the underlying cause of death and additional fields for other causes. One may show placement on the death certificate, that is, underlying cause and other diagnoses on lines A, B, C, D, Part 1, or Part 2. Finally, one may have underlying cause with reordering and defining the role and type of every cause, such as underlying, intermediate, terminal, contributory, associated, risk factor, etc.

My presentation was adapted from a workshop of 4 weeks ago to discuss multiple causes and is a way to resume the discussion concerning rules and standards for multiple coding.

Thank you.

Multiple Causes of Death: Definitions and Coding Rules

Dr. Ruy Laurenti, WHO Collaborating Center, University of São Paulo, Brazil and Cassia Maria Buchalla, Ph.D., WHO Collaborating Center and School of Public Health, University of São Paulo, Brazil

Introduction

The importance of analyzing mortality using underlying cause and multiple causes of death is well recognized. Even John Graunt in his classic work of 1662, *Natural and Political Observations Made Upon the Bills of Mortality*, made some comments on ''dying due to a disease'' and ''dying with a disease.'' The importance of tabulations by multiple causes is based on the fact that rarely is a death due to only one cause. Therefore, to have a picture of the status of a population using mortality indicators, it would be best to tabulate all the diseases and complications present at the moment of death.

One can give many examples of mortality analysis according to multiple causes. One study carried out on deaths in hospitals in São Paulo, for instance, showed that diabetes mellitus was associated with hypertension in 33.7 percent of the cases, with ischemic heart diseases in 31.3 percent, with cerebrovascular diseases in 42.8 percent, with malignant neoplasias in only 2.6 percent of cases, and with infectious diseases in 19.5 percent.

The same study showed that when a hypertensive disease was mentioned on the death certificate, it was reported with diabetes (13 percent), ischemic heart disease (29.3 percent), cerebrovascular diseases (66.1 percent), and arterial diseases (31.8 percent). Another study analyzing death certificates of adults in São Paulo showed that hypertension was selected as the underlying cause in 2.7 percent of the cases; however, it was mentioned in 30 percent of the cases.

Successive reviews in ICD recommend analyzing mortality in terms of multiple causes. Thus, in ICD–6 (approved in 1948), a ''Suggested Form of Multiple Cause Tabulation'' was presented. The ICD–7 includes a reference to multiple causes of death; ICD–8 presents a specific recommendation in the ''Report of the International Conference for the Eight Revision'' with respect to multiple causes (see item 2.5 ''Multiple Cause Tabulation and Analysis''). ICD–9 and ICD–10 also refer to the tabulation and analyses of mortality by multiple causes. In spite of all that has been said and published, very little has been done in terms of routinely publishing mortality statistics according to multiple causes, which would be very beneficial in epidemiology and health services management.

Mortality analysis by multiple causes

In recent years, software for the tabulation of multiple causes has been developed, presented and discussed. However, these discussions do not deal with definitions, standards, and guidelines for coding multiple causes. The adoption of definitions and standards is vital and necessary to develop software to tabulate multiple causes.

At the meeting of Heads of WHO Collaborating Centers for the Classification of Diseases in Uppsala, 1988, the Pan American Health Organization (PAHO) presented the paper, ''A Suggested Methodology for Multiple Causes (DES/IC/C/88–38)'' with proposals for definitions and rules for coding multiple causes. At the meeting of Heads of WHO Collaborating Centers for the Classification of Diseases in Washington, 1993, the Brazilian Center presented a paper (SES/ICD/C/93–7) discussing multiple causes and the slow advance we have had even though the issue has been discussed in several papers, and the Center Heads supported the PAHO proposal. These definitions and rules from the earlier papers are presented below as a base for discussion.

Definitions

Intervening causes: All conditions precipitated by the underlying cause.

Importance: If sometimes the underlying cause cannot be easily prevented, it may be more feasible to prevent complications or conditions precipitated by the underlying cause.

Conditioning causes: Those conditions that actually initiate the chain of events leading to death when the originating cause is not the underlying cause.
Importance: Sometimes due to coding requirements, the real originating cause is hidden. It is important to know the real primary cause for preventive purposes.
Contributory causes: All those conditions that are not part of the chain leading to death but that contribute to it.
Importance: The knowledge of those conditions is important to study co-causal factors.
Associated causes: All other conditions, which are neither underlying causes, intervening causes, conditioning causes, nor contributory causes.
Importance: The knowledge of those other conditions is complementary in the study of the net of causality.

Rules for coding multiple causes

Intervening cause

I(b) If the underlying cause is selected by application of Rule 1 and no modifications have been made, assume that all the conditions entered in the sequence above the underlying cause are intervening causes.

I(c) If the underlying cause was selected by General Principle or Rules 1, 2, or 3 and modified by Rules A or B, apply rules I(a) or I(b) depending on the way the new underlying cause was reselected. Disregard the ill-defined conditions.

I(d) If the underlying cause selected by General Principle or Rule 1, 2, or 3 was modified by Rule C, proceed as follows:

If the underlying cause has the same code of any disease in the certificate, assume that the sequence starts at this level and apply I(a) or I(b) depending on the rule previously applied.

If the underlying cause has a different code from all the diseases in the certificate, apply I(a) or I(b) underlying cause.

I(e) If the underlying cause of death was selected by General Principle or Rules 1 or 2 and modified by rule D or E, apply rules I(a) or I(b) on the previously selected cause taking into account the selections rules applied. Disregard the real underlying cause and the selected cause.

Conditioning cause

C(a) When the underlying cause selected by General Principle or Rule 1 is modified by Rule C by linkage with any disease entered above the selected cause, take the previously selected cause as conditioning cause.

C(b) When the selected cause is due to a cause that has been disregarded because of the ''Guides for the determination of the probability of sequences,'' take this ''highly improbable'' condition as the conditioning cause. It does not apply to highly improbable conditions due to dates of onset.

Contributory cause

D(a) Select the cause or causes listed on Part II of the certificate, unless they were taken into account to apply modification Rules C or 3.

D(b) If the underlying cause is a disease entered in Part II of the certificate and there are conditions other than in Part II, select the other conditions in Part II as contributing causes.

Associated cause

A(c) Select all the other causes entered on the certificate that were not selected as underlying, intervening, conditioning, or contributory.

Diabetes Mellitus: Differential Multiple-Causes-of-Death Mortality Among the States of Rio De Janeiro and São Paulo (Brazil), Australia, England and Wales, Scotland, and the United States of America

Dr. Augusto Hasiak Santo, University of Sã[00e3]o Paulo, Brazil

Introduction

This paper is about differential multiple causes of death among the states of Rio, São Paulo, Australia, England, Wales, Scotland, and the United States regarding diabetes mellitus. To prepare this paper, in addition to Brazilian data, I gathered data from members of the planning committee of the ICE and others. Some countries could not send me data because of legal issues. I acknowledge Anne Wellington, Peter Borg, and Eddy Anderson from Australia.

Cause of death is different among regions due to epidemiological factors, circumstances related to the certification of death, and procedures for coding and processing data. Diabetes mellitus is only selected as the underlying cause about one-third of the times it appears on death certificates, but it is very often mentioned on death certificates. Papers on diabetes with multiple causes of death are common, and they are often based on multiple causes.

The objectives of this paper are to compare the differences in causes of death related to diabetes across the regions we mentioned before. We call ''associated causes'' those that are non-underlying causes. ''Non-underlying cause'' is the name used in the U.S. for ''associated cause.''

Data sources and problems

The data came from official vital statistics offices of the participating regions. Diabetes includes codes E10 to E14 of ICD–10. Causes of death were processed by multiple-cause-of-death software that Celso Escobar Pinheiro and I developed, which is a tabulator for underlying cause of death. Another software program that looks for associated causes and will make a separate file of only associated causes is called ''Death Records Tabulator,'' and it is not yet published.

To present the associated causes, a list of the most frequently associated causes and of the causes related to the natural history of diabetes was prepared. This list was used by the Tabulator to display the associated cause of death. With software developed by Gambesi and distributed by the Pan American Health Organization (PAHO), death rates were standardized using the world population.

While developing this paper, I had some difficulties. For instance, the data file that I received was in ASCII flat text and comma-separated. Some software programs have difficulty recognizing text files, so there are problems running these files. My intention was to present causes of death; thus, I asked for only causes of death, which did not necessarily have accompanying documentation. When I began to receive comments and suggestions from the participants (some requested data by age, for standardization of age, for sex, etc.), I had documentation for the Brazilian file but not for all of the other country files. For the U.S. file we had good documentation that allowed us to check whatever we were doing. There were control totals so that if we found a different value, we could check whether or not our software was good or assess any other difficulty. The Australian report is exemplary; I use it in courses on multiple causes of death. This is another example of good documentation.

Regarding ''axis coding,'' at first I had not asked for multiple-cause data in any particular axis. However, in Brazil, we do not have ''record-axis'' data; we only have ''entity-axis'' codes, so when I received ''record-axis'' codes from some countries, they were not comparable with the Brazilian data. Thus, you will see on Table 2 how in one country record-axis codes and notations appeared. TRANSAX removes some codes from records, so it is going to be hard to see vascular diseases.

Finally, all countries used different field names and had different field sizes, which were additional problems.

Results

Table 1 presents a synthesis of the data, including the year of the data, the population of each country, the numbers, the total number of deaths of each country, the type of condition codes, the number of causes by death certificate, etc.

Table 1 - Data specifications about the differential study on diabetes multiple causes of death mortality, States of Rio de Janeiro and São Paulo (Brazil), Australia, England & Wales, Scotland and United States of America.

Data specifications	Rio de Janeiro	São Paulo	Australia	England/Wales	Scotland	United States
Year of data	2000	2000	2001	2001	2000	1999
Population	14,391,282	37,032,403	19,485,278	52,084,800	5,058,200	272,690,871
Number of total deaths	103,443	239,963	128,545	528,236	57,799	2,394,871
Type of condition codes	entity axis	entity axis	entity axis	entity axis	entity axis	entity axis
Mean number of causes by Death Certificate (SD)	2.84 (±1.41)	3.05 (±1.34)	3.09 (±1.68)	2.30 (±1.19)	2.55 (±1.25)	2.83 (±1.61)
Diabetes: underlying cause of death	4,832	8,702	3,078	6,119	616	68,462
Diabetes: associated (non-underlying) causes of death	3,645	12,311	7,246	18,882	2,598	141,525
Diabetes: total mentions on Death Certificates	8,477	21,013	10,324	25,001	3,214	209,987
Diabetes: ratio of mentions/underlying cause	1.8	2.4	3.4	4.1	5.2	3.1
Diabetes: mean number of causes by Death Certificate (SD)	3.56 (±1.18)	3.94 (±1.18)	3.66 (±1.39)	3.36 (±1.16)	3.73 (±1.25)	3.86 (±1.53)
Diabetes: rate by 100.000 population as underlying cause (CI)	31.9 (31.6-32.0)	26.2 (26.2-26.3)	8.2 (8.2-8.2)	4.8 (4.8-4.8)	5.5 (5.5-5.6)	14.3 (14.3-14.3)
Diabetes: rate by 100.000 population as total mentions (CI)	55.9 (55.8-56.0)	63.2 (63.1-63.3)	27.3 (27.3-27.3)	19.9 (19.8-19.9)	28.4 (28.2-28.5)	42.7 (42.7-42.7)
Diabetes: proportional mortality as underlying cause (%)	4.7	3.6	2.4	1.2	1.1	2.9
Diabetes: proportional mortality as total mentions (%)	8.2	8.8	8.0	4.7	5.6	8.8

Sources: Department of Informatics of the Public Health System, Ministry of Health, Brazil.
São Paulo State System for Data Analysis Foundation, Brazil
Australian Bureau of Statistics
Office of National Statistics, United Kingdom.
General Register Office for Scotland
National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services.
(SD) = Standard deviation
(CI) = Confidence interval

Diabetes figures are also shown as follows: underlying cause, diabetes-associated causes, the ratio of mentions to the underlying cause, the mean number of causes, and the proportion of all deaths in each country. Thus, for Rio de Janeiro the standardized death rate for diabetes (underlying cause) is 31.9 and for England it is 4.8; the rate varies greatly around the world.

Table 2, which was prepared with the multiple-cause-of-death tabulator, shows the distribution of associated causes among countries. Ischemic heart disease is higher in England, Australia, Scotland, and the United States.

Table 2 - Number and percentages of deaths from diabetes according to their associated causes of death, States of Rio de Janeiro and São Paulo (Brazil), Australia, England & Wales, Scotland and United States of America.

Associated (non underlying) causes of death *	Rio de Janeiro (deaths = 4,832)		São Paulo (deaths = 8,702)		Australia (deaths = 3,078)		England & Wales (deaths = 6,119)		Scotland (deaths = 616)		United States (deaths = 68,462)	
	Nº	%	Nº	%	Nº	%	Nº	%	Nº	%	Nº	%
Septicaemias (A40-A41)	837	17.3	1,196	13.7	279	9.1	625	10.2	54	8.8	5,812	8.5
Metabolic disorders (E70-E89)	382	7.9	814	9.4	191	6.2	85	1.4	15	2.4	3,954	5.8
Hypertensive diseases (I10-I13)	1,667	34.5	2,729	31.4	166	5.4	635	10.4	84	13.6	16,587	24.2
Ischaemic heart diseases (I20-I25)	646	13.4	1,804	20.7	1,579	51.3	2,129	34.8	280	45.5	29,524	43.1
Conduction and rhythm disorders (I44-I49)	257	5.3	980	11.3	473	15.4	262	4.3	44	7.1	17,225	25.2
Heart failure (I50)	469	9.7	1,302	15.0	530	17.2	861	14.1	80	13.0	11,409	16.7
Cerebrovascular diseases (I60-I69)	919	19.0	1,646	18.9	678	22.0	1,193	19.5	111	18.0	10,779	15.7
Diseases of arteries, arterioles and ... (I70-I78)	266	5.5	813	9.3	115	3.7	998	16.3	139	22.6	9,291	13.6
Pneumonias (J12-J18)	425	8.8	1,414	16.2	292	9.5	830	13.6	91	14.8	4,273	6.2
Respiratory failure (J96)	1,042	21.6	1,363	15.7	52	1.7	20	0.3	1	0.2	2,136	3.1
Renal failure (N17-N19)	760	15.7	2,009	23.1	690	22.4	1,261	20.6	155	25.2	19,800	28.9
Gangrene (R02)	176	3.6	193	2.2	20	0.6	272	4.4	26	4.2	1,881	2.7
Other associated causes of death	2,723	56.4	5,181	59.5	1,576	51.2	3,017	49.3	316	51.3	31,009	45.3
TOTAL	10,569	NC	21,444	NC	6,641	NC	12,188	NC	1,396	NC	163,680	NC

Sources: Department of Informatics of the Public Health System, Ministry of Health, Brazil.
São Paulo State System for Data Analysis Foundation, Brazil
Australian Bureau of Statistics
Office of National Statistics, United Kingdom
General Register Office for Scotland
National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services.

* Rubrics and codes of the International Statistical Classification of Diseases e Related Health Problems, Tenth Revision
% Percentages related to the number of deaths.
NC = not calculated.

Table 3 shows diabetes as an associated cause of death with the underlying cause of death in the first column.

Table 3 - Number and percentages of deaths with diabetes as an associated (non-underlying) cause according to their underlying cause, States of Rio de Janeiro and São Paulo (Brazil), Australia, England and Wales, Scotland and United States of America.

Underlying causes of death	Rio de Janeiro		São Paulo		Australia		England & Wales		Scotland		United States	
	Nº	%	Nº	%	Nº	%	Nº	%	Nº	%	Nº	%
Septicaemias (A40-A41)	105	2.9	157	1.3	78	1.1	115	0.6	8	0.3	2,312	1.6
Other infectious and parasitic diseases (A00-B39, A42-B99)	74	2.0	301	2.4	37	0.5	71	0.4	6	0.2	1,388	1.0
Neoplasms (C00-D48)	410	11.2	1,251	10.2	1,516	20.9	2,651	14.0	415	16.0	20,445	14.4
Hypertensive diseases (I10-I13)	287	7.9	692	5.6	117	1.6	249	1.3	30	1.2	5,176	3.7
Ischaemic heart diseases (I20-I25)	611	16.8	2,721	22.1	2,599	35.9	7,237	38.3	1,039	40.0	55,261	39.0
Other forms of heart disease (I30-I51)	249	6.8	1,139	9.3	371	5.1	905	4.8	98	3.8	9,047	6.4
Cerebrovascular diseases (I60-I69)	715	19.6	2,020	16.4	836	11.5	2,808	14.9	412	15.9	13,288	9.4
Diseases of arteries, arterioles and capillaries (I70-I78)	59	1.6	207	1.7	85	1.2	177	0.9	26	1.0	1,561	1.1
Pneumonias (J12-J18)	182	5.0	988	8.0	150	2.1	1,172	6.2	76	2.9	3,101	2.2
Chronic lower respiratory diseases (J40-J47)	203	5.6	653	5.3	323	4.5	662	3.5	75	2.9	6,468	4.6
Other diseases of the respiratory system (J00-J99)	205	5.6	327	2.7	98	1.4	402	2.1	45	1.7	2,221	1.6
Diseases of liver (K70-K77)	66	1.8	254	2.1	84	1.2	160	0.8	28	1.1	1,861	1.3
Other diseases of the digestive system (K00-K93)	141	3.9	591	4.8	141	1.9	427	2.3	83	3.2	2,913	2.1
Diseases of the genitourinary system (N00-N99)	76	2.1	230	1.9	221	3.0	452	2.4	63	2.4	4,357	3.1
External causes of morbidity and mortality (V01-Y98)	60	1.6	84	0.7	130	1.8	166	0.9	37	1.4	2,065	1.5
Other underlying causes of death	202	5.5	696	5.7	460	6.3	1,229	6.5	157	6.0	10,061	7.1
TOTAL	3,645	100.0	12,311	100.0	7,246	100.0	18,883	100.0	2,598	100.0	141,525	100.0

Sources: Department of Informatics of the Public Health System, Ministry of Health, Brazil.
São Paulo State System for Data Analysis Foundation, Brazil
Australian Bureau of Statistics
Office of National Statistics, United Kingdom.
General Register Office for Scotland
National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services.
* Rubrics and codes of the International Statistical Classification of Diseases e Related Health Problems, Tenth Revision

Conclusion

The conclusions, of course, are that we can gain very much insight using multiple-cause-of-death analysis and that diabetes is not a disease equally reported around the world.

Thank you very much.

Comments

C. ROONEY: I thought it was very striking that in the underlying cause statistics there is more than a six-fold difference between the country with the lowest mortality rate from diabetes, which seems to be England and Wales, and the highest, which is Brazil. Whereas when you go to the multiple cause, the difference between the highest and the lowest is about two and a half times. Do you think that is because the disease is different, the certificates are written differently, or the selection rules are applied differently?

DR. SANTO: It is very difficult to answer this question because I do not know how physicians certify deaths in other countries. In Brazil we use the tables of the ACME that have undergone some adaptations. You may notice also that the numbers of causes of death vary greatly. England has the lowest rate of conditions per death certificate, which may influence these differences. To better answer this question, we should sit down now and see what happens in every country.

Disease Patterns in Multiple-Cause Data at Advanced Ages: United States 1980–1998

Eric Stallard, A.S.A., M.A.A.A., Center for Demographic Studies, Duke University, Durham, North Carolina, U.S.

Introduction

I want to thank the organizers, especially Bob Anderson, for inviting me to make this presentation. I also want to thank the National Institute on Aging for support of this research. In the planning discussions, Bob Anderson asked me to make the presentation new, to make it exciting, and to make it simple. I will try to do all three of those things today.

Let me deal with the ''new'' part first. The presentation expands upon results in my July 2002 paper in the *North American Actuarial Journal* (NAAJ) available online at www.soa.org (Stallard, 2002). When I wrote that paper, I did an extensive literature search on the use of multiple-cause mortality data. The most surprising finding was how few articles had been published on the topic over the past 20 years. My expectation is that most of you will not be familiar with the methods and results of analyses of multiple-cause mortality data, and I am hoping that you will be surprised by at least some of the results in the presentation.

Let me deal with the ''simple'' part next. To facilitate the presentation, I prepared handouts that are identical to the slides, except that the handouts include an Appendix. Twenty of the 36 slides in the presentation contain graphical displays of the analytic results. The Appendix contains eight tables from the NAAJ paper displaying summary measures for individual causes of death by age, sex, and year. Given the time constraints and the goal of making the presentation simple, I will not comment further on the Appendix materials.

Methods

With these simplifications, my goal today is to make the presentation sufficiently new and exciting that you are motivated to pursue the details on your own after I have finished. The analysis focuses on the calendar period 1980–1998, a period during which U.S. mortality data were coded using the *Ninth Revision of the International Classification of Diseases* (ICD–9). The analysis focuses on 14 major causes of death, which I will talk about shortly. The analysis focuses on the elderly population, primarily because I have done almost all of my prior research on the elderly; so, it appeared best to focus on age groups where I already had significant analytic experience.

Four fundamental measures can be used to characterize individual-level microdata records containing computerized coding of cause-of-death data from death certificates. All four measures can be described as ''death rates,'' and for all four measures the denominators typically are the mid-year population in the demographic groups under analysis. The numerators of such death rates are distinguished by the source of the information used in the tabulations. The first measure uses underlying-cause-of-death (UC) mortality data in forming the numerators of death rates. This is the measure used in almost all national vital statistics reports, and it is the measure assumed to be used unless clearly stated to be otherwise. The second measure uses multiple-cause-of-death (MC) mortality data in forming the numerators of death rates. This measure is based on the complete set of causes of death recorded and computer coded (using the ''record-axis'' algorithm) from the cause-of-death section of the death certificate (e.g., see Section 6 of the U.S. Standard Certificate of Death). The third measure uses associated-cause-of-death (AC) mortality data in forming the numerators of death rates. The associated causes comprise all causes other than the underlying cause and are identified by listing the entire set of MC causes and then deleting the UC cause.

Table 1 – Disease Definitions for Underlying and Multiple Cause of Death Tabulations

#	Cause of Death	Category Codes – ICD-9
1	Diseases of heart	390-398, 402, 404, 410-429
2	Malignant neoplasms	140-208
3	Cerebrovascular diseases	430-438
4	Chronic obstructive pulmonary diseases	490-496
5	Pneumonia and influenza	480-487
6	Diabetes mellitus	250
7	Suicide	E950-E959
8	Nephritis, nephrotic syndrome, and nephrosis	580-589
9	Chronic liver disease and cirrhosis	571
10	Septicemia	038
11	Alzheimer's disease	331.0
12	Atherosclerosis	440
13	Hypertension with or without renal disease	401, 403
14	Aortic aneurysm	441
15	Residual causes of death	All codes not listed above

Source: Based on Murphy (2000) and Hoyert et al. (2001).

In calculating the MC and AC death rates, it is significant to note that there may be more than one listed cause of death per decedent. In my applications, I recode the MC conditions to the 14 categories listed in Table 1 (above), insert the corresponding recode of the UC code (to guard against a remote possibility that the UC recode would not appear among the MC recodes), and then remove all duplicate recodes to obtain a unique unduplicated sequence of conditions. This allows the AC conditions to be unambiguously defined and also allows consideration of the joint occurrences of one or more MC conditions. The ''record-axis'' coding of the MC conditions is generally done without recording information on the order of the conditions in the cause-of-death section of the death certificate, and that procedure was followed in my tabulations.

The fourth measure uses the joint occurrences of two or more MC conditions in constructing the numerators of the death rates. With 14 MC conditions plus a residual category, there are 15 x 4 = 210 pairs of such conditions, which reduces to 105 distinct pairs because the order of the conditions is not preserved. Similarly, there are 15 x 14 x 13 = 2,730 triples of such conditions, which reduces to 455 distinct triples with duplicates removed. Because the joint occurrences represent a unique aspect of multiple-cause mortality data, I focused this presentation on the lessons that can be learned from studying this particular measure of mortality.

I hate suspense, so I am going to tell you right now what you learn. What you learn is that the causes of death are not independent. This is important if you assume each UC condition is the sole causative agent in the mortality process. Such an assumption is implicit in conventional methods for computing the number of years of life lost due to each cause of death. In fact, this assumption is consistent with the standard definition of the underlying cause of death, as: ''(a) The disease or injury which initiated the train of events leading directly to death, or (b) the circumstances of the accident or violence which produced the fatal injury.''

In contrast, associated conditions may be conditions that resulted from the indicated underlying-cause condition (''Part I conditions'') or conditions that contributed to death but did not result from the underlying-cause condition (''Part II conditions''). The computer-based record-axis coding provides a listing of

all distinct medical conditions in a form comparable with the underlying-cause codes, but in a form that does not preserve sequence information from Part I of the death certificate.

Once it is recognized that MC conditions may appear as either AC conditions or as UC conditions, it follows that MC conditions may have different roles in mortality, that individual MC conditions may be amalgamations of heterogeneous medical conditions, and that there may be dependencies between MC conditions that had not been recognized previously. Disease dependencies are well recognized in clinical practice but such dependencies have received little attention in statistical reports prepared from national mortality data. Disease dependencies are in no way forced on the data just because multiple causes are reported on the death certificate. Disease dependencies among the multiple causes reported on the death certificate could motivate further investigation into the nature of such dependencies and may serve to inform clinical practice.

To the extent that the various diseases, conditions, or causes are not independent, one could ask how appropriate is it to follow the death certification rules which require the certifier to designate one or more of the reported conditions as a ''cause'' or as ''the cause'' of death. If the various diseases, conditions, or causes are in fact dependent, then specific combinations of MC conditions may indicate the actions of one or more fundamental biomedical processes that are responsible both for the death and for the dependency patterns among the reported MC conditions. These are fundamental issues that require thoughtful consideration.

We now need to briefly discuss the data. For this analysis, I used NCHS death certificate microdata records for 1980, 1990, and 1998. These files contained death certificate reports for all 2.0–2.3 million deaths each year in the United States, including the 1.3–1.8 million deaths among persons aged 65 and older. The exposed population was estimated using corresponding midyear population counts obtained from the U.S. Bureau of the Census. The Census counts were adjusted via extinct cohort calculations (based on the NCHS mortality counts) to complete the population data series to age 105. These adjustments were motivated by concerns about the reliability of census data counts at extreme old ages. However, they are actually of little consequence for the analyses presented today.

Table 1, as already presented, lists the 14 causes of death used in the analysis along with the ICD–9 codes used to define the cause-of-death categories. A fifteenth cause was defined as the residual category for all ICD–9 codes not explicitly included in defining the first 14 causes. The residual category allowed the tabulations to include all deaths in the selected age and sex groups, which facilitated verification of the accuracy of our tabulation procedures by reference to independent control tables. In addition, the residual category completed the set of possible outcomes in considering the joint dependencies of the MC conditions.

These procedures are fully general in the sense that they could be applied to any list of conditions defined using ICD–9 codings of the MC conditions. The specific list indicated in Tables 2–4 was derived from two NCHS lists. I combined NCHS's 1998 top 15 underlying causes with NCHS's 1999 top 15 underlying causes. In so doing, I dropped accidents and homicide because those were external causes, and I wanted to look at conditions that reflected internal physiology. I added aortic aneurysm because that was new to the 1999 list, and I restricted the list to 14 defined conditions (or 15, with residual causes included) because a count of the total number of cells in my largest table indicated that I was working with 23 million cells. Adding just one additional defined condition would have raised the total to 46 million cells, and that would have exceeded the capacity of my processing software. Once the exploratory analyses have been done, it would be reasonable to consider longer lists of conditions. This could necessitate updates to the tabulation software and/or increased computer memory.

Figure 1.

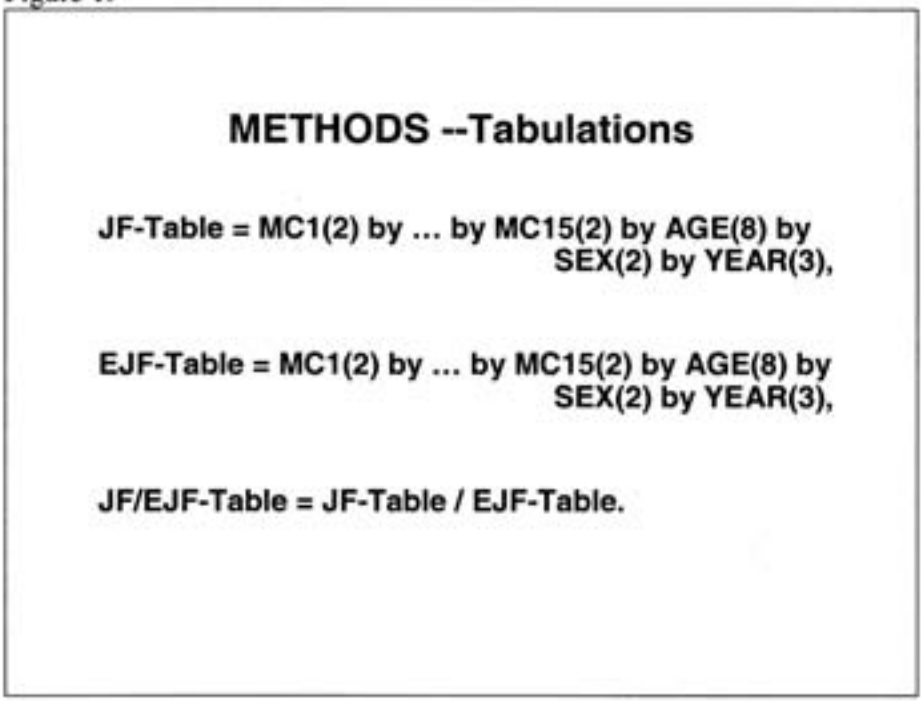


Figure 1 (above) provides summary specifications for the two types of tabulations employed in the analysis. ‘‘JF’’ is a mnemonic for ‘‘joint frequency.’’ ‘‘JF-Table’’ denotes a joint frequency tabulation. The JF-Table specified in Figure 1 is an 18-dimensional table comprising 15 dimensions, one each for the 15 medical conditions, and 1 dimension each for age, sex, and year. Each death certificate record in the analysis generates an increment to exactly 1 of the 1,572,864 cells in the table, where $1,572,864 = 2^{15} \times 8 \times 2 \times 3$.

To construct the joint-frequency table, one must define 15 binary indicators, one for each of the 15 conditions listed in Table 1. In processing each death certificate record, one sets the first indicator to 1 if the first condition appears on the MC condition field of the death certificate; otherwise, one sets the first indicator to 0. One sets the second indicator to 1 if the second condition appears on the MC condition field of the death certificate; otherwise, one sets the second indicator to 0. One repeats this procedure for the remaining 13 indicators. At this point, the JF-Table can be incremented at the appropriate cell indexed by the combination of the 15 indicators, age, sex, and year, to include the information from the current death certificate record. This procedure defines the basic tabulation, which is an 18-dimensional table. Whether you are using your own programs or vendor software, I recommend that you perform verification tests to ensure the accuracy of the tabulations. I have seen software and compilers for multidimensional tables that fail to produce correct results with more than six dimensions.

In Figure 1, ‘‘EJF’’ is the mnemonic for ‘‘expected joint frequency.’’ ‘‘EJF-Table’’ denotes the expected values of the counts in the JF-Table containing the associated joint frequency tabulation. Following Bob Anderson’s request to keep things simple, the expected values of the joint frequencies were based on the assumption that the causes of death were independent, within combinations of age, sex, and year. Under independence, the fraction of deaths that mention one condition can be multiplied by the fraction of deaths that mention some other condition to produce the fraction of deaths that mention the pair of conditions. For example, consider one condition that is mentioned in half of the death certificates and one that is mentioned in 10 percent of the death certificates. Under independence, the pair of conditions would be expected to be jointly mentioned in five percent of the death certificates. The computation of the expected joint frequency of each pair of conditions is a simple multiplication that can be understood by most people. Moreover, it does not matter whether you have two conditions, three conditions, or more than three conditions, you are just

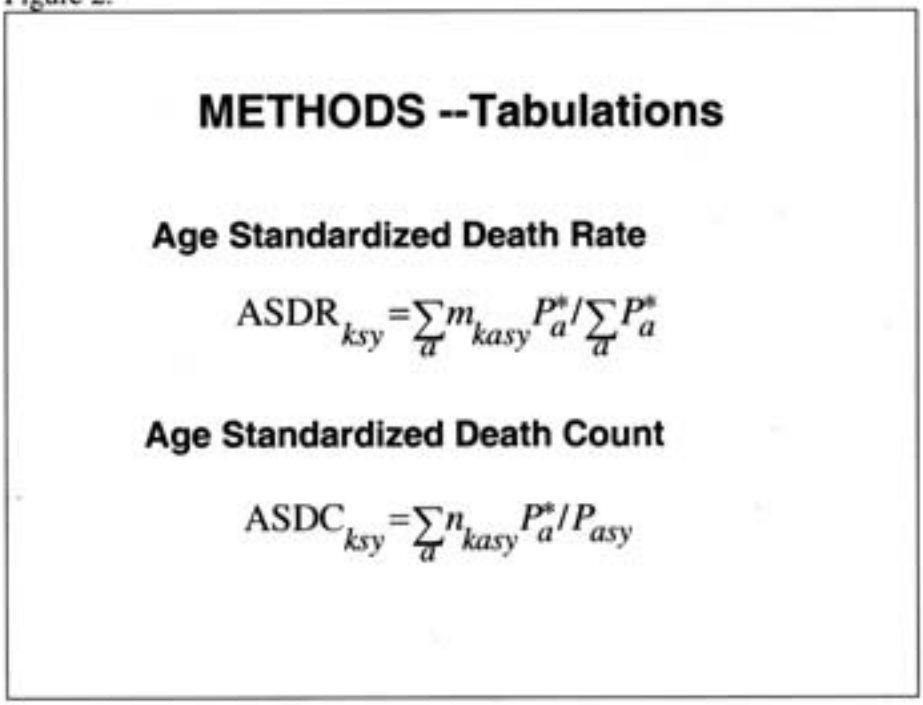
multiplying fractions. With three conditions, you compute the expected fraction of deaths that mention a given triple by multiplying the fraction of deaths that mention the first condition by the fraction that mention the second condition, and then multiplying the result by the fraction that mention the third condition. As the number of conditions being jointly considered increases, the expected-value fractions get smaller. Nonetheless, when you have 1.3–1.8 million records per year as the total number over the 16 combinations of age and sex, you can tolerate small fractions. For the EJF-Table, the expected-value fractions were computed for the joint occurrences of 15 conditions. These were converted to expected-value counts by multiplying each fraction by the number of deaths in the corresponding combination of age, sex, and year categories. Finally, ''JF/EJF-Table'' is the mnemonic for the table of the ratios of the observed to expected joint frequencies. These ratios can be constructed for any combination of two conditions, three conditions, or more than three conditions by first summing the JF-Table and the EJF-Table over those conditions that are not part of the selected combination (yielding a smaller marginal table) and then computing the observed/expected ratios for the retained combinations on a cell-by-cell basis (i.e., within the resulting pairs of marginal JF- and EJF-Tables). This can be tedious, but not difficult, if the number of pairs, triples, etc., is large.

Demographers, epidemiologists, gerontologists, statisticians, and actuaries all are familiar with ratios of observed to expected counts, standardized mortality rates, standardized morbidity ratios, and similar measures. In each case, one takes the observed number and divides it by the expected number. Under the independence assumptions for joint frequencies of MC conditions, if the observed/expected ratio is 1.0, then the conditions are independent. If the ratio is not 1.0, then the conditions are dependent.

Many analysts are familiar with the calculation of correlation coefficients and correlation matrices. In tabulating the JF-Table, one needs to code 15 binary indicator variables, one for each of the 15 conditions used in the analysis. In addition, one could construct a 15 x 15 correlation matrix containing the pairwise correlation coefficients for the 15 indicator variables for each combination of age, sex, and year. Because the 0–1 coding of the indicator variables restricts the matrix of raw sums and squares of cross products to include only those death certificates where pairs of conditions are both present, it follows that the observed/expected ratio attains the value 1.0 at precisely the same point as the correlation coefficient is 0.0. Positive values of the correlation coefficient correspond to observed/expected ratios greater than 1.0; and negative values to observed/expected ratios less than 1.0.

In the context of the present analysis, the observed/expected ratios are easier to interpret than are correlation coefficients. Moreover, the observed/expected ratios can be computed for triples and higher order combinations of conditions whereas no similar generalization exists for correlation coefficients.

Figure 2.



In order to make valid cross-temporal comparisons, one needs to age-standardize the observed/expected ratios. Therefore, we now need to briefly discuss age standardization methods. Figure 2 (above) presents the usual formula for the age-standardized death rate (ASDR) for condition k in sex s in year y, defined as the death rate that would occur in a standard population $\{P^*_a\}$, where a denotes age, under the schedule of age-specific death rates {mkasy}, where, observed for condition k at age a in sex s in year y, and where {nkasy} is the set of age-specific death counts observed for condition k at age a in sex s in year y and {Pasy} is the corresponding set of exposed population counts.

The denominator of the age-standardized death rate is constant for all rates computed in the analysis; only the numerator varies over sex and year. If one retains only the numerator of the age-standardized death rate, the result is a quantity that can be characterized as an age-standardized death count (ASDC). Hence, ASDCs and ASDRs contain equivalent information. We focus on ASDCs because the present analysis greatly simplifies if the standardization uses ASDCs rather than ASDRs. The ASDC formula can be applied to both the JF-Tables and the EJF-Tables to compute age-standardized observed/expected ratios for pairs and triples of MC conditions. All that is required is that the condition subscript *k* be redefined in the ASDC formula as an index for the 105 pairs of MC conditions, in the case of pairwise occurrences of the 15 conditions; as an index for the 455 triples of MC conditions, in the case of 3-way occurrences of the 15 conditions; or as a higher order index in the case of combinations of 4 or more conditions.

Results

Table 2 – Ratios of Observed to Expected Age-Standardized Joint Frequencies of Multiple Causes: Unisex Mortality 1990, Age 65+

	Multiple Cause														
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
# Multiple Cause	Heart Dis.	Malign Neopl	CBV Dis.	COP Dis.	Pneu Influ	Diabt Mellit	Suicid	Nephrit Nephro	Chr.Liv Cirrho	Septic -emia	Alzhm Dis.	Athero -scler	Hyper -tens	Aortic Aneur	Resid Dis.
1 Diseases of heart	–	0.52	0.75	1.04	0.75	1.18	0.09	0.93	0.67	0.68	0.64	0.95	1.03	0.80	0.87
2 Malignant neoplasms	0.52	–	0.29	0.61	0.77	0.46	0.14	0.83	0.41	0.86	0.19	0.35	0.36	0.28	0.87
3 Cerebrovascular diseases	0.75	0.29	–	0.53	1.07	1.28	0.05	0.58	0.34	0.74	0.90	1.43	1.92	0.41	0.92
4 ChrObstructivePulDis	1.04	0.61	0.53	–	1.47	0.55	0.14	0.79	0.75	0.57	0.43	0.77	0.66	0.75	1.23
5 Pneumonia and influenza	0.75	0.77	1.07	1.47	–	0.86	0.07	1.05	0.92	1.69	2.27	0.86	0.59	0.36	1.16
6 Diabetes mellitus	1.18	0.46	1.28	0.55	0.86	–	0.08	1.33	0.82	1.18	0.60	1.40	2.14	0.34	0.86
7 Suicide	0.09	0.14	0.05	0.14	0.07	0.08	–	0.04	0.12	0.05	0.00	0.06	0.06	0.01	2.34
8 Nephritis/Nephrosis	0.93	0.83	0.58	0.79	1.05	1.33	0.04	–	1.79	2.48	0.45	1.03	0.36	1.58	1.31
9 ChronLiverDis/Cirrhosis	0.67	0.41	0.34	0.75	0.92	0.82	0.12	1.79	–	1.21	0.07	0.53	0.51	0.38	1.73
10 Septicemia	0.68	0.86	0.74	0.57	1.69	1.18	0.05	2.48	1.21	–	1.20	0.60	0.47	0.63	1.73
11 Alzheimer's disease	0.64	0.19	0.90	0.43	2.27	0.60	0.00	0.45	0.07	1.20	–	0.88	0.49	0.27	1.09
12 Atherosclerosis	0.95	0.35	1.43	0.77	0.86	1.40	0.06	1.03	0.53	0.60	0.88	–	1.59	0.83	0.96
13 Hypertension	1.03	0.36	1.92	0.66	0.59	2.14	0.06	0.36	0.51	0.47	0.49	1.59	–	1.76	0.86
14 Aortic aneurysm	0.80	0.28	0.41	0.75	0.36	0.34	0.01	1.58	0.38	0.63	0.27	0.83	1.76	–	1.01
15 Residual causes	0.87	0.87	0.92	1.23	1.16	0.86	2.34	1.31	1.73	1.73	1.09	0.96	0.86	1.01	–

Table 3 – Ratios of Observed to Expected Age-Standardized Joint Frequencies of Multiple Causes: Unisex Mortality 1990, Age 65+

	Multiple Cause														
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
# Multiple Cause	Heart Dis.	Malign Neopl	CBV Dis.	COP Dis.	Pneu Influ	Diabt Mellit	Suicid	Nephrit Nephro	Chr.Liv Cirrho	Septic -emia	Alzhm Dis.	Athero -scler	Hyper -tens	Aortic Aneur	Resid Dis.
1 Diseases of heart	–	0.52	0.81	1.01	0.75	1.25	0.10	1.05	0.66	0.70	0.71	1.06	1.13	0.87	0.88
2 Malignant neoplasms	0.52	–	0.31	0.68	0.70	0.47	0.19	0.84	0.42	0.71	0.30	0.30	0.47	0.24	0.81
3 Cerebrovascular diseases	0.81	0.31	–	0.56	1.05	1.40	0.07	0.63	0.31	0.83	0.69	1.89	2.17	0.47	0.95
4 ChrObstructivePulDis	1.01	0.68	0.56	–	1.48	0.66	0.22	0.70	0.65	0.66	0.50	0.78	0.65	0.68	1.23
5 Pneumonia and influenza	0.75	0.70	1.05	1.48	–	0.86	0.04	1.03	0.72	1.76	1.77	0.63	0.61	0.30	1.19
6 Diabetes mellitus	1.25	0.47	1.40	0.66	0.86	–	0.10	1.63	0.94	1.18	0.68	1.62	2.49	0.32	0.89
7 Suicide	0.10	0.19	0.07	0.22	0.04	0.10	–	0.03	0.17	0.04	0.07	0.10	0.10	0.05	2.20
8 Nephritis/Nephrosis	1.05	0.84	0.63	0.70	1.03	1.63	0.03	–	1.79	2.06	0.54	1.25	0.31	1.33	1.22
9 ChronLiverDis/Cirrhosis	0.66	0.42	0.31	0.65	0.72	0.94	0.17	1.79	–	1.24	0.18	0.42	0.54	0.38	1.68
10 Septicemia	0.70	0.71	0.83	0.66	1.76	1.18	0.04	2.06	1.24	–	1.20	0.55	0.58	0.59	1.56
11 Alzheimer's disease	0.71	0.30	0.69	0.50	1.77	0.68	0.07	0.54	0.18	1.20	–	0.93	0.65	0.34	1.00
12 Atherosclerosis	1.06	0.30	1.89	0.78	0.63	1.62	0.10	1.25	0.42	0.55	0.93	–	1.69	0.96	0.93
13 Hypertension	1.13	0.47	2.17	0.65	0.61	2.49	0.10	0.31	0.54	0.58	0.65	1.69	–	1.98	0.94
14 Aortic aneurysm	0.87	0.24	0.47	0.68	0.30	0.32	0.05	1.33	0.38	0.59	0.34	0.96	1.98	–	0.98
15 Residual causes	0.88	0.81	0.95	1.23	1.19	0.89	2.20	1.22	1.68	1.56	1.00	0.93	0.94	0.98	–

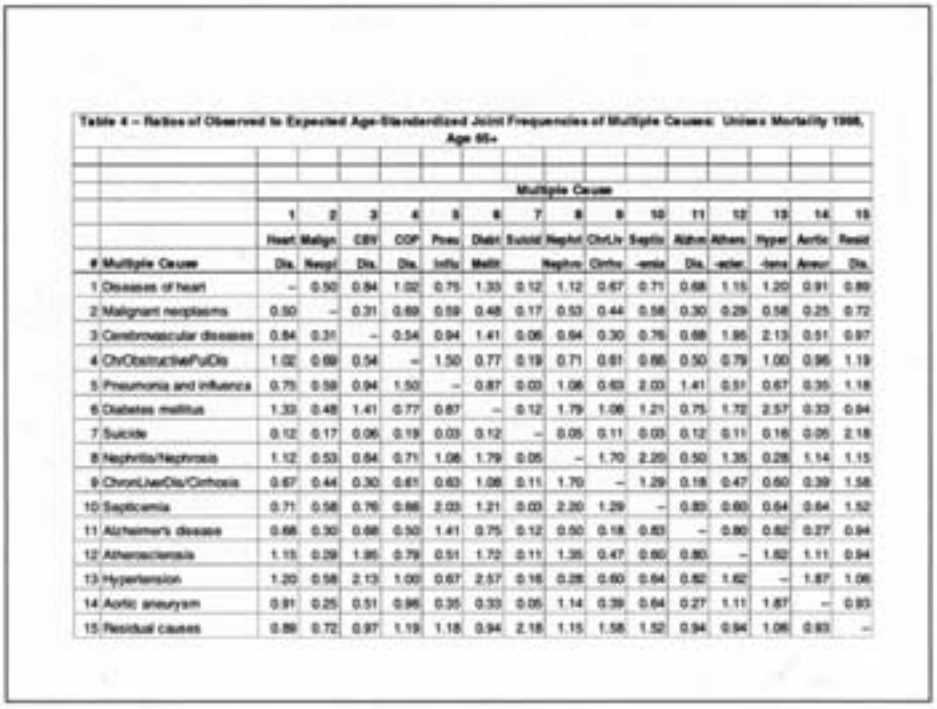


Table 4 – Ratios of Observed to Expected Age-Standardized Joint Frequencies of Multiple Causes: Unisex Mortality 1998, Age 65+

		Multiple Cause														
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
		Heart	Malign	CBV	COP	Pneu	Diabt	Suicid	Nephrt	ChrLiv	Septic	Alzhm	Athero	Hyper	Aortic	Resid
#	Multiple Cause	Dis.	Neopl	Dis.	Dis.	Infls	Mellit		Nephro	Cirrho	-emia	Dis.	-scler	-tens	Aneur	Dis.
1	Diseases of heart	–	0.50	0.84	1.02	0.75	1.33	0.12	1.12	0.67	0.71	0.68	1.15	1.20	0.91	0.89
2	Malignant neoplasms	0.50	–	0.31	0.69	0.59	0.48	0.17	0.53	0.44	0.58	0.30	0.29	0.58	0.25	0.72
3	Cerebrovascular diseases	0.84	0.31	–	0.54	0.94	1.41	0.06	0.94	0.30	0.76	0.68	1.95	2.13	0.51	0.97
4	ChrObstructivePulDis	1.02	0.69	0.54	–	1.50	0.77	0.19	0.71	0.61	0.66	0.50	0.79	1.00	0.96	1.19
5	Pneumonia and influenza	0.75	0.59	0.94	1.50	–	0.87	0.03	1.06	0.63	2.03	1.41	0.51	0.67	0.35	1.18
6	Diabetes mellitus	1.33	0.48	1.41	0.77	0.87	–	0.12	1.79	1.06	1.21	0.75	1.72	2.57	0.33	0.94
7	Suicide	0.12	0.17	0.06	0.19	0.03	0.12	–	0.05	0.11	0.03	0.12	0.11	0.16	0.05	2.18
8	Nephritis/Nephrosis	1.12	0.53	0.94	0.71	1.06	1.79	0.05	–	1.70	2.20	0.50	1.35	0.28	1.14	1.15
9	ChronLiverDis/Cirrhosis	0.67	0.44	0.30	0.61	0.63	1.06	0.11	1.70	–	1.29	0.18	0.47	0.60	0.39	1.58
10	Septicemia	0.71	0.58	0.76	0.66	2.03	1.21	0.03	2.20	1.29	–	0.80	0.60	0.64	0.64	1.52
11	Alzheimer's disease	0.68	0.30	0.68	0.50	1.41	0.75	0.12	0.50	0.18	0.83	–	0.80	0.82	0.27	0.94
12	Atherosclerosis	1.15	0.29	1.95	0.79	0.51	1.72	0.11	1.35	0.47	0.60	0.80	–	1.62	1.11	0.94
13	Hypertension	1.20	0.58	2.13	1.00	0.67	2.57	0.16	0.28	0.60	0.64	0.62	1.62	–	1.87	1.06
14	Aortic aneurysm	0.91	0.25	0.51	0.96	0.35	0.33	0.05	1.14	0.39	0.64	0.27	1.11	1.87	–	0.93
15	Residual causes	0.89	0.72	0.97	1.19	1.18	0.94	2.18	1.15	1.58	1.52	0.94	0.94	1.06	0.93	–

The age-standardized observed/expected ratios for pairs of MC conditions are shown separately by year in slides Tables 2–4 (above) for the 105 distinct pairwise combinations of the 15 MC conditions. Table 2 shows the 1980 unisex table; Table 3 the 1990 unisex table; and Table 4 the 1998 unisex table. Because there are far too many ratios to discuss individually at this time, I considered how to graphically display the most salient results. To do so, I focus on the 1998 results in Table 4.

Figures 3–16 (below) illustrate one approach to presentation of the results. One graph is presented for each of the first 14 conditions listed in the column headings in Table 4. Each graph displays the observed/expected ratios in the 14 non-empty rows of the selected column in Table 4 in descending rank order. Under the assumptions of the model, ratios greater than 1.0 imply positive association or correlation of the pair of conditions; ratios below 1.0 imply negative association or correlation; and ratios equal to 1.0 imply independence of the conditions. To illustrate, consider Figure 3, which displays the observed/expected ratios for all conditions paired with diseases of the heart. The observed/expected ratios for diseases of the heart paired with diabetes, hypertension, atherosclerosis, and nephritis/nephrosis are all above 1.0; the ratio for diseases of the heart paired with chronic obstructive pulmonary diseases is near 1.0; and the ratios for diseases of the heart paired with everything else are below 1.0.

Figure 3.

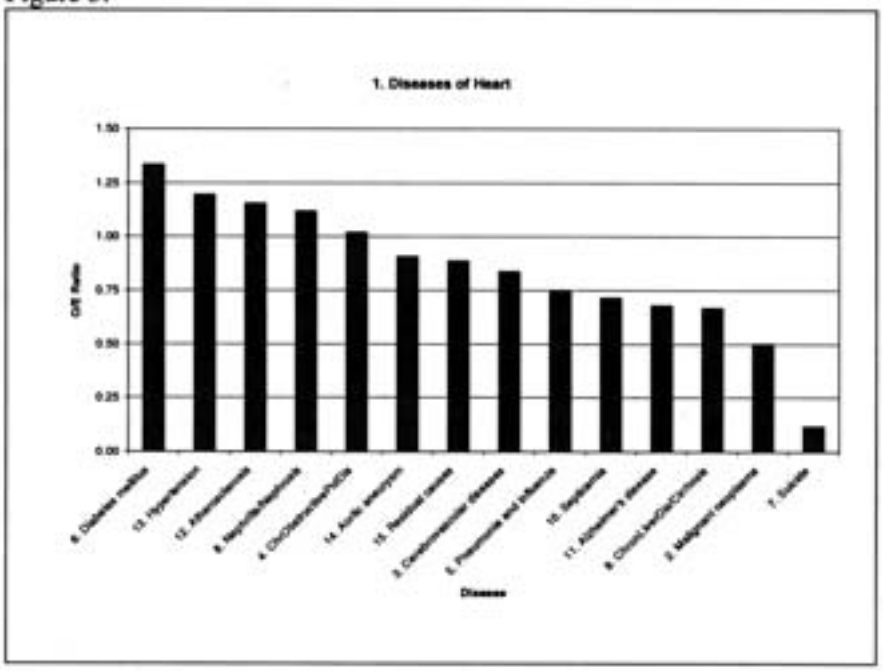


Figure 4.

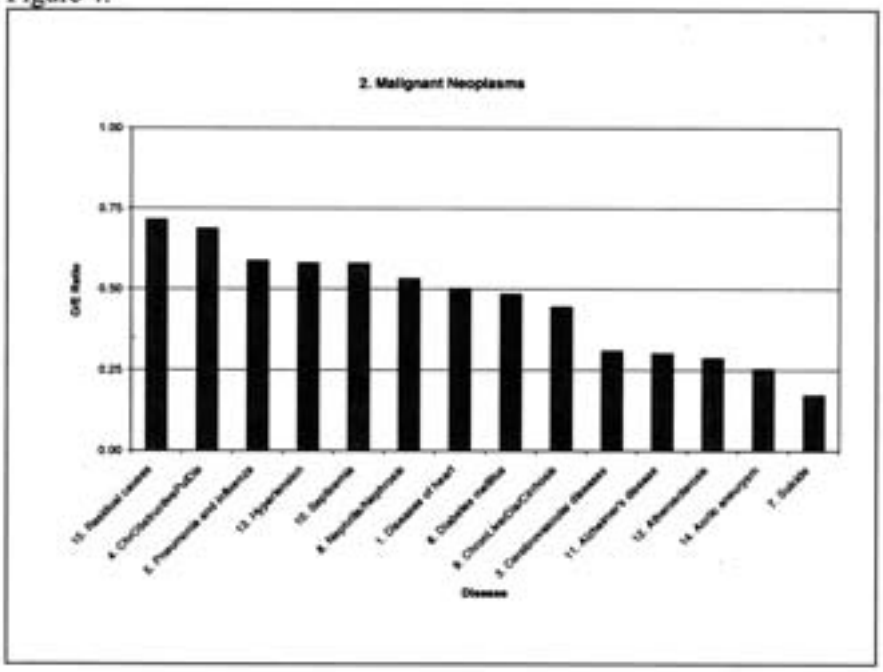


Figure 5.

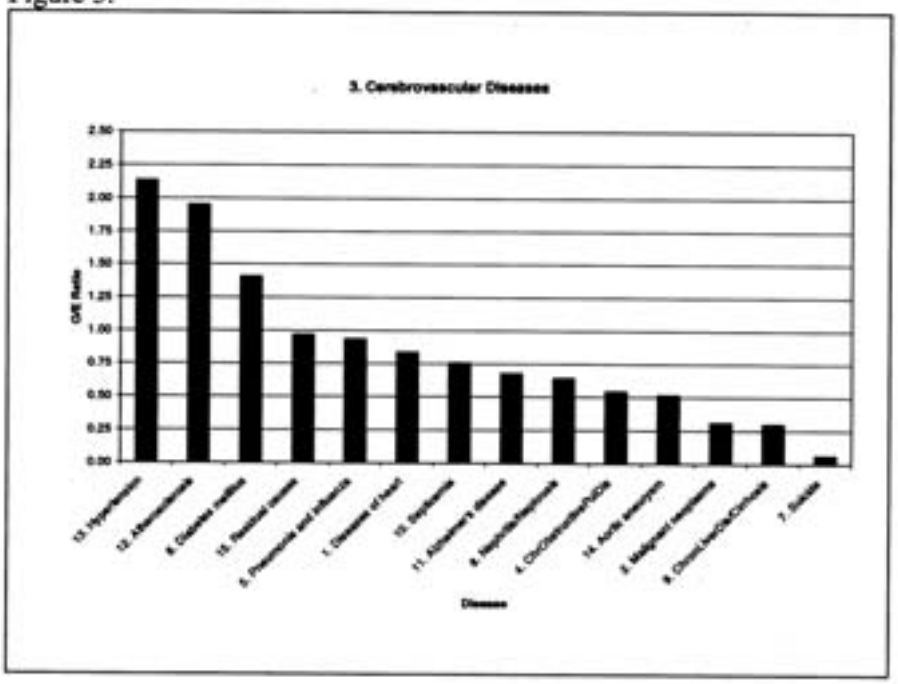


Figure 6.

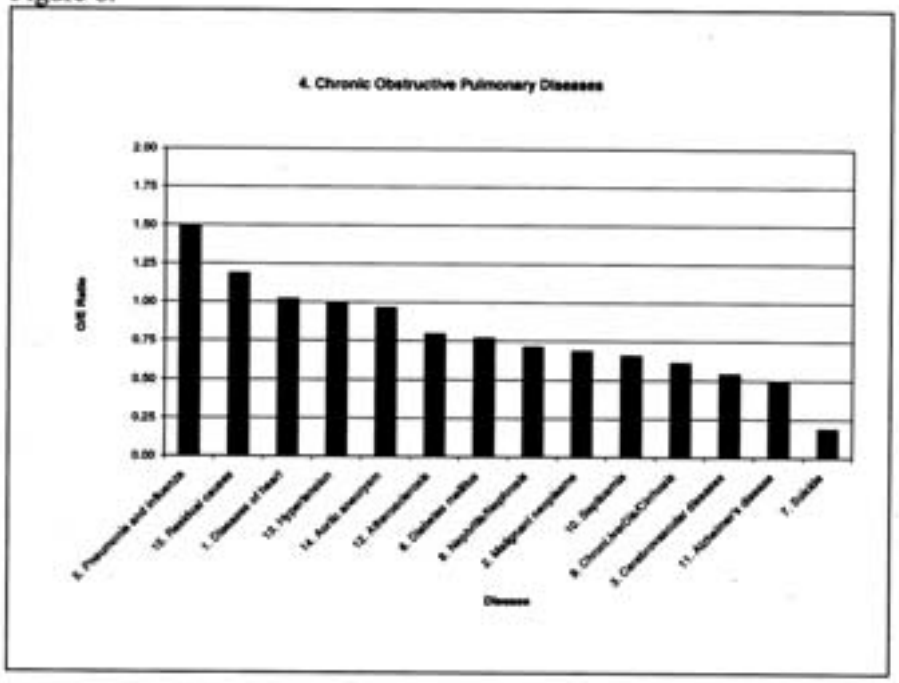


Figure 7.

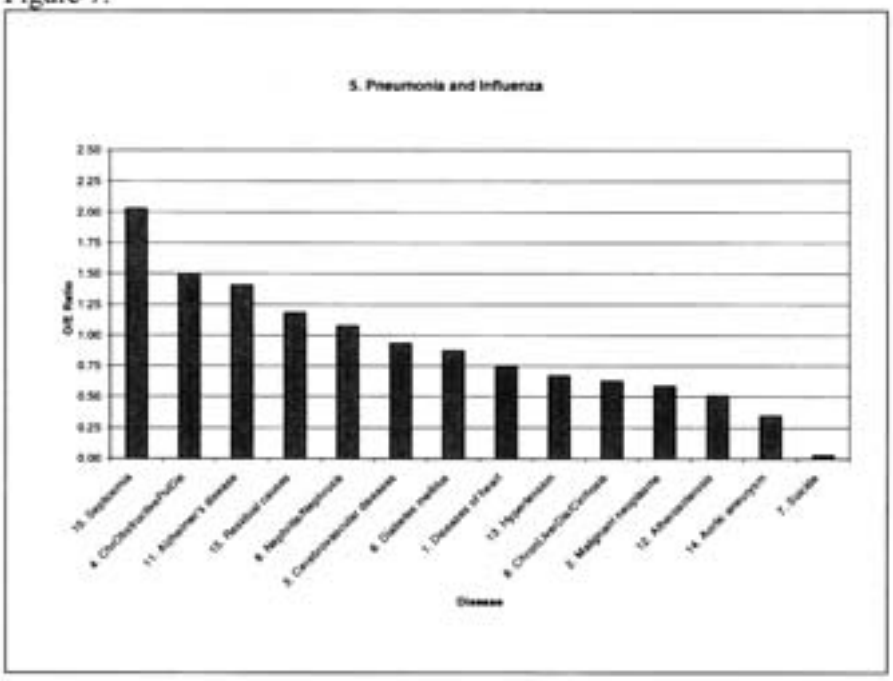


Figure 8.

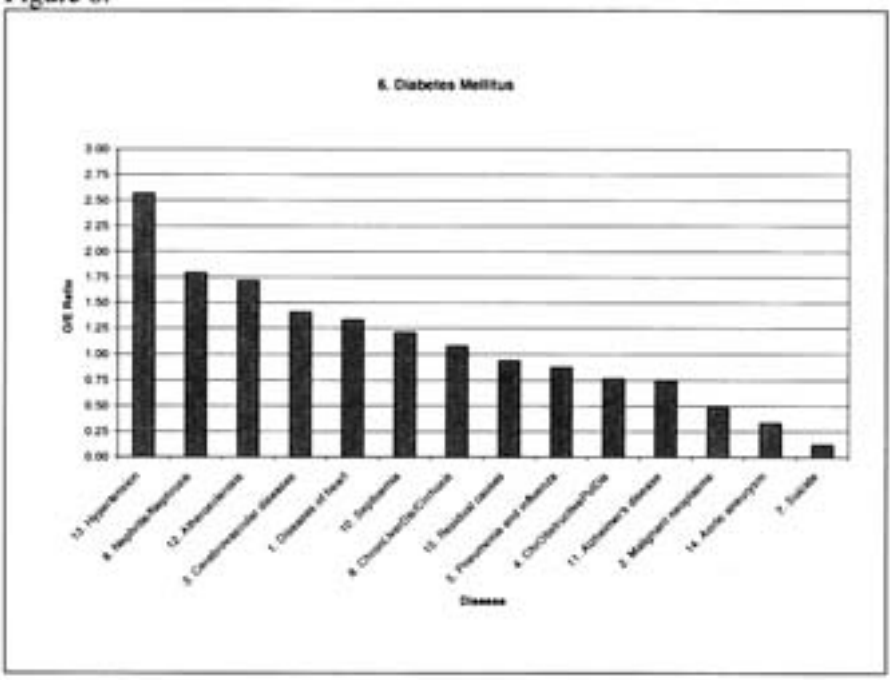


Figure 9.

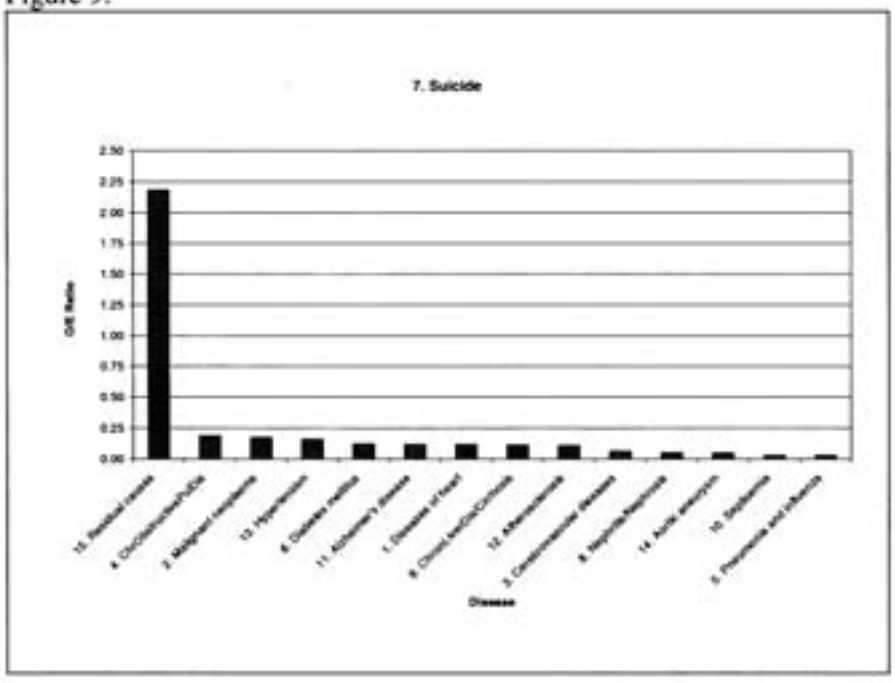


Figure 10.

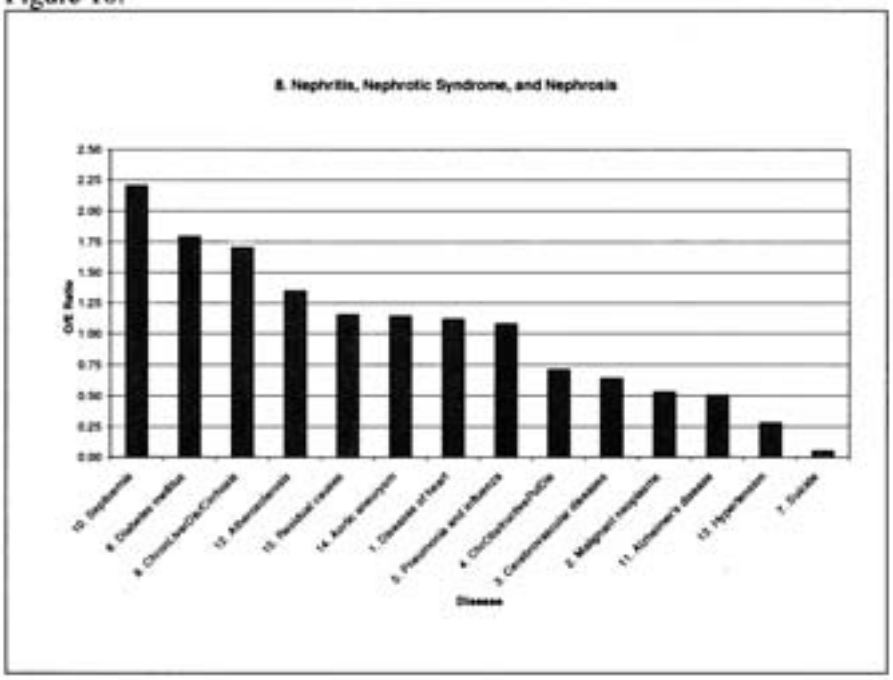


Figure 11.

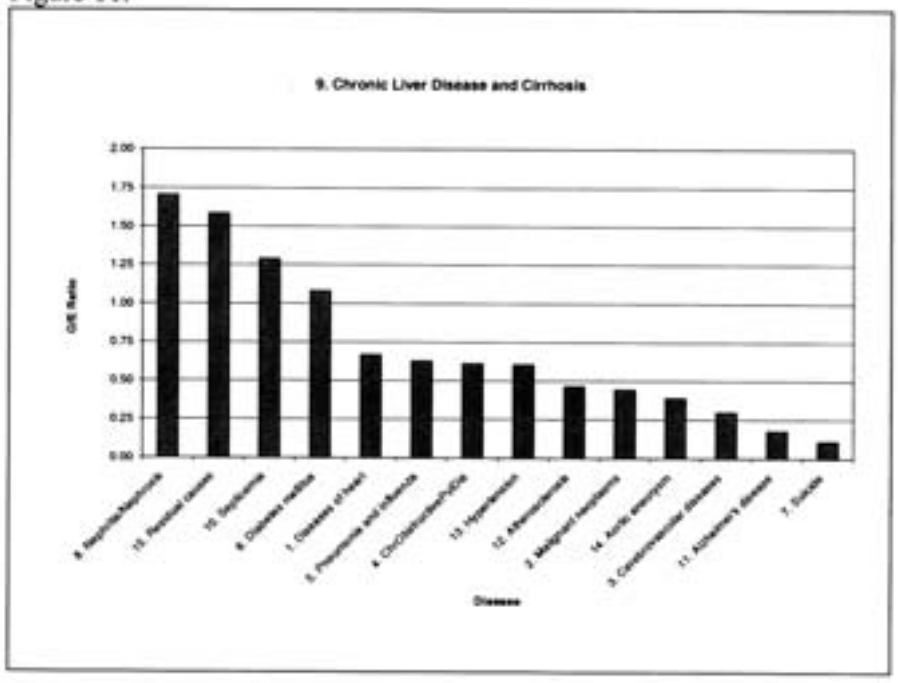


Figure 12.

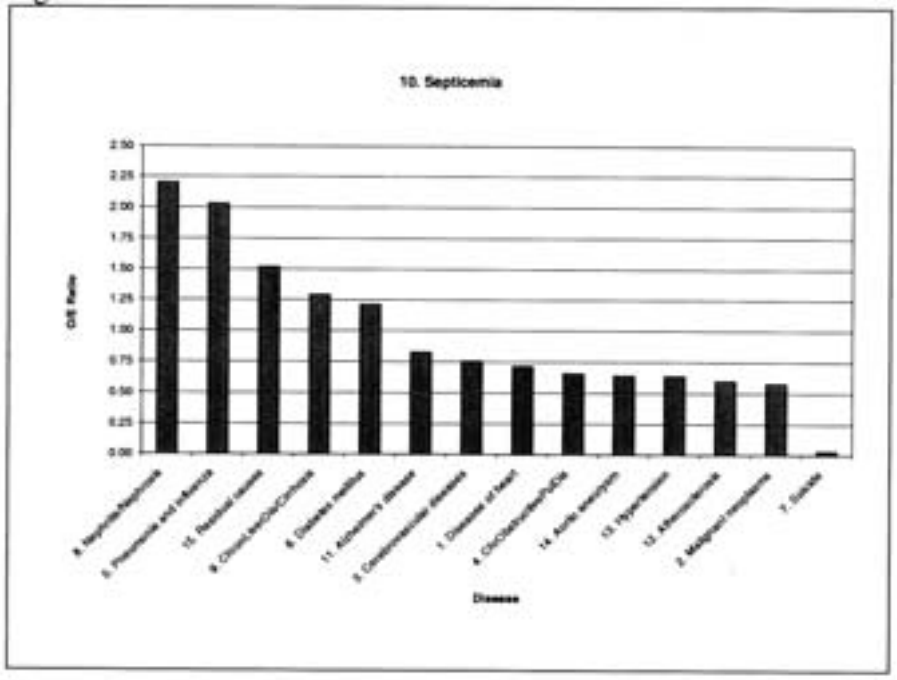


Figure 13.

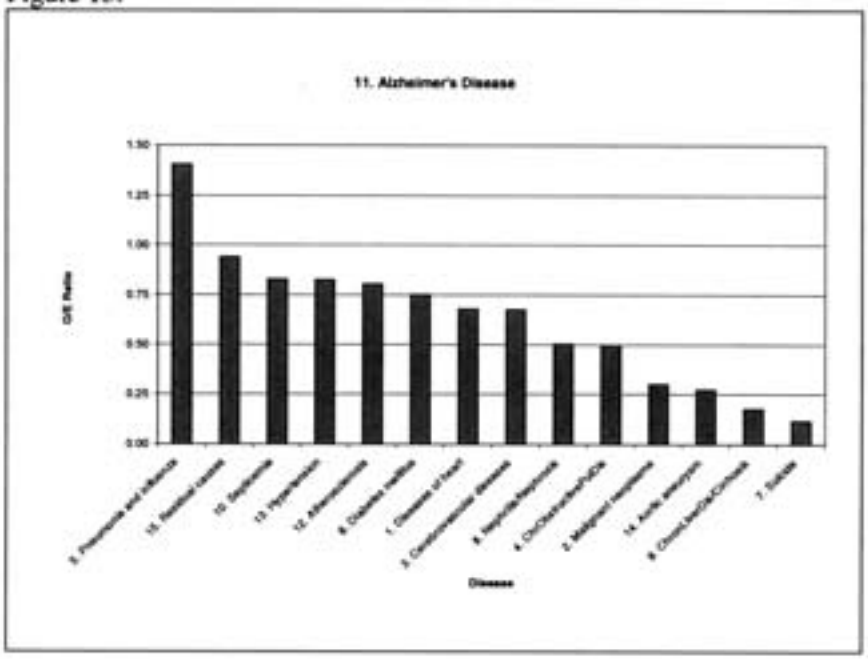


Figure 14.

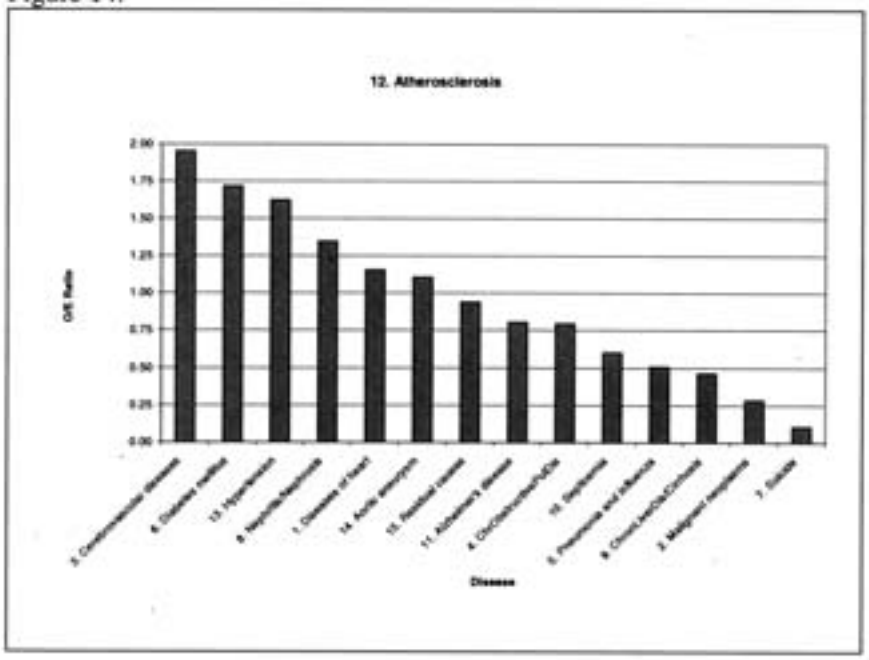


Figure 15.

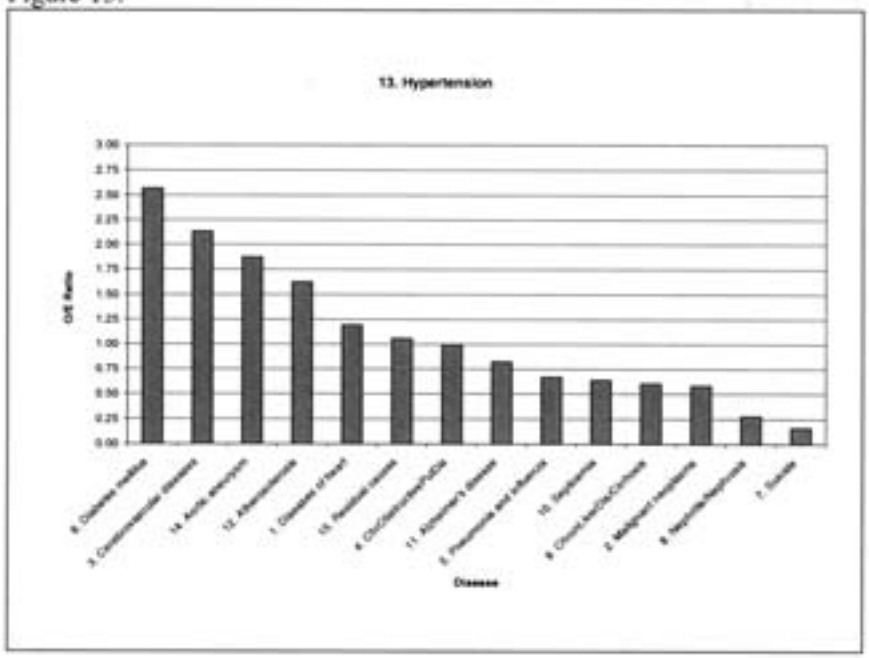
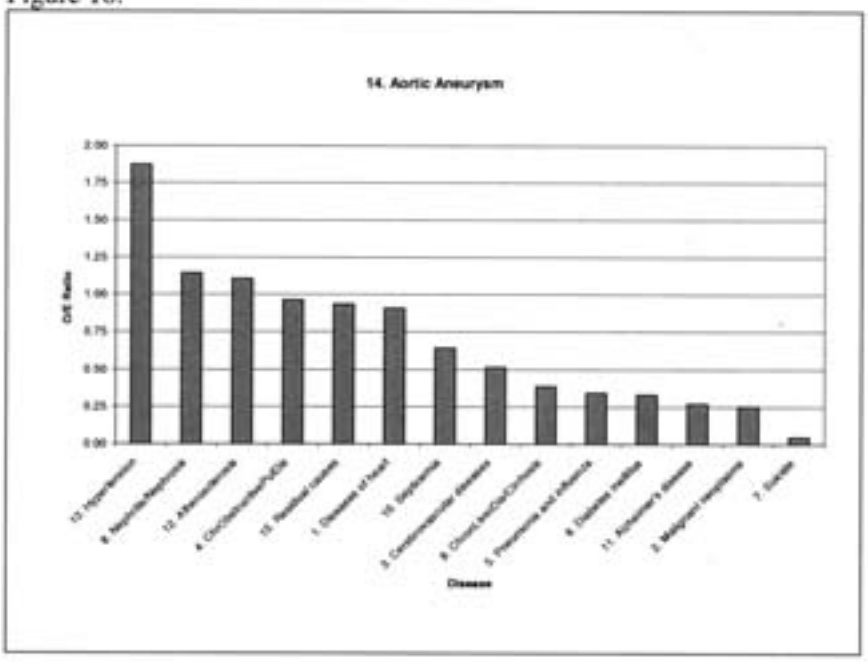


Figure 16.



Because of the nature of the reporting process, it is possible theoretically to have a mortality process where one condition acting alone was sufficient to cause death, in which case one would never see a second condition. Consideration of such processes may help in the interpretation of some of the lower ratios. However, the same argument does not apply to explain ratios that are greater than 1.0, so for every pair for which the observed/expected ratio is above 1.0 there is a higher than expected association or a positive correlation, which violates the assumption of independence and which can not be attributed to the constraints of the reporting process. With respect to diseases of the heart, diabetes and hypertension have the strongest positive associations. Both conditions are well-known risk factors for diseases of the heart and the observed association is consistent with clinical knowledge.

Figure 4 shows that all ratios for cancer are below one, and in fact are below 0.75. This indicates that the ratios for independent pairs of conditions may in truth be below 1.0, which could occur if the death certification process excluded conditions that were medically significant but not lethal. Figure 5 shows some very high ratios for cerebrovascular diseases, where the pairing with hypertension yields an observed/expected ratio of 2.1. Atherosclerosis (1.9 ratio) and diabetes (1.4 ratio) are the second- and third-ranked conditions paired with cerebrovascular diseases. Figure 6 displays the ratios for chronic obstructive pulmonary diseases. The pairwise association with pneumonia/influenza has the highest observed/expected ratio at 1.5. Residual causes rank second, with no other positive pairwise associations. For pneumonia and influenza (Figure 7), by symmetry, the pairwise association with chronic obstructive pulmonary diseases has the same 1.5 ratio—which ranks second behind septicemia, with a 2.0 ratio. For diabetes (Figure 8), the pairwise associations with hypertension, nephritis/nephrosis, and atherosclerosis are the three top-ranked associations. The hypertension ratio of 2.6 is a fairly high multiplier and indicates that these pairs are occurring at a rate far higher than expected under the independence assumption. Suicide (Figure 9) needs some additional explanation. In U.S. coding practice, and I expect for many other countries, the nature-of-injury code (N-code) is coded with each suicide. As a result, each suicide is recorded with at least two ICD–9 conditions, with the N-code included in the residual-causes category using the list of causes in Table 1. Figure 9 shows that the observed/expected ratio for the joint occurrence of suicide and residual causes is 2.2, which is the only positive association shown. The ratios for the combinations of suicide with the remaining 13 conditions are all substantially below 0.2. I had expected to obtain higher ratios for at least some of the 13 conditions, but it is clear now that the associations that are reported are relatively low.

Figures 10–16 display pairwise positive associations in rank order as follows:

- For nephritis/nephrosis (Figure 10)—with septicemia, diabetes, chronic liver disease, and atherosclerosis.
- For chronic liver disease (Figure 11)—with nephritis/nephrosis, residual causes, and septicemia.
- For septicemia (Figure 12)—with nephritis/nephrosis, pneumonia/influenza, residual causes, chronic liver disease, and diabetes.
- For Alzheimer's disease (Figure 13)—with pneumonia/influenza.
- For atherosclerosis (Figure 14)—with cerebrovascular diseases, diabetes, hypertension, nephritis/nephrosis, diseases of the heart, and aortic aneurysm.
- For hypertension (Figure 15)—with diabetes, cerebrovascular diseases, aortic aneurysm, atherosclerosis, and diseases of the heart.
- For aortic aneurysm (Figure 16)—with hypertension, nephritis/nephrosis, and atherosclerosis.

Figures 17–22 (below) display selected results from the observed/expected joint frequency ratios based on associations of combinations of sets of three conditions. The format is the same as in the previous figures where the title of each graph identifies one condition that is part of all of the combinations in that graph. The condition names at the bottom of each graph represent the 14 pairs of conditions that combine with the title condition to form the 14 triple combinations with the highest-ranked observed/expected joint frequency ratios.

Figure 17.

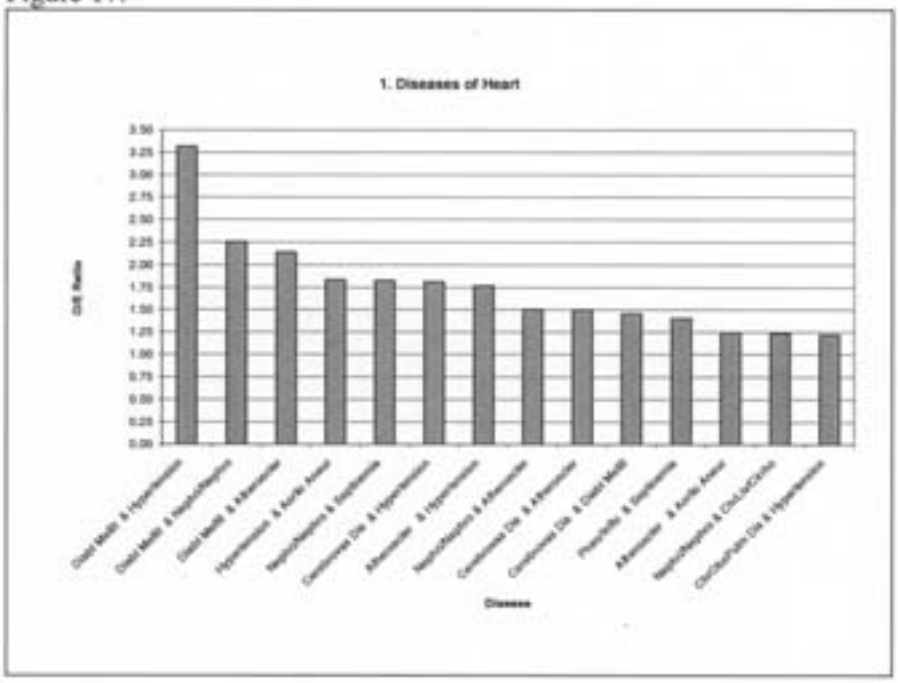


Figure 18.

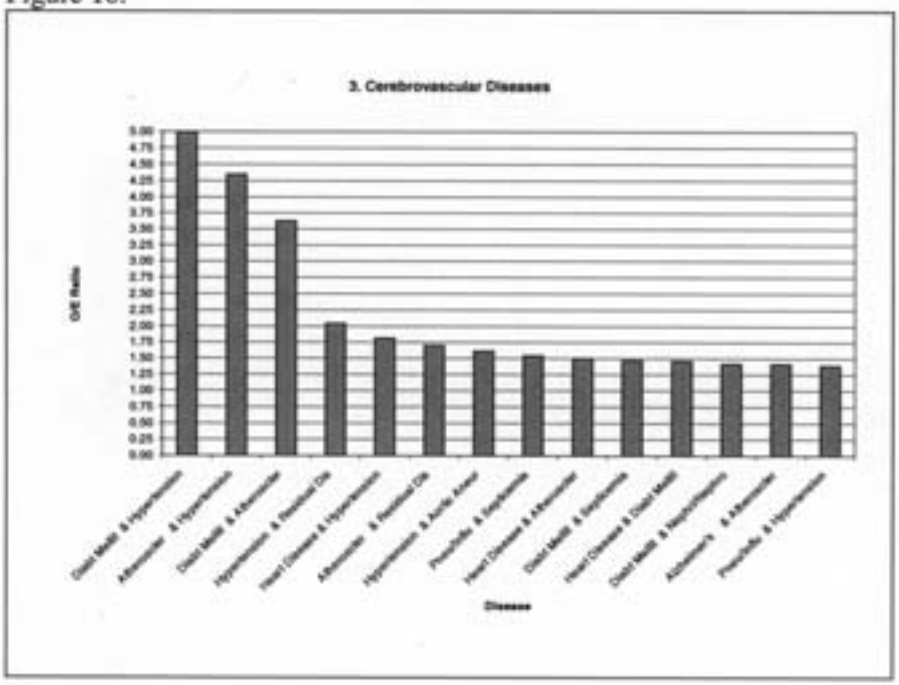


Figure 19.

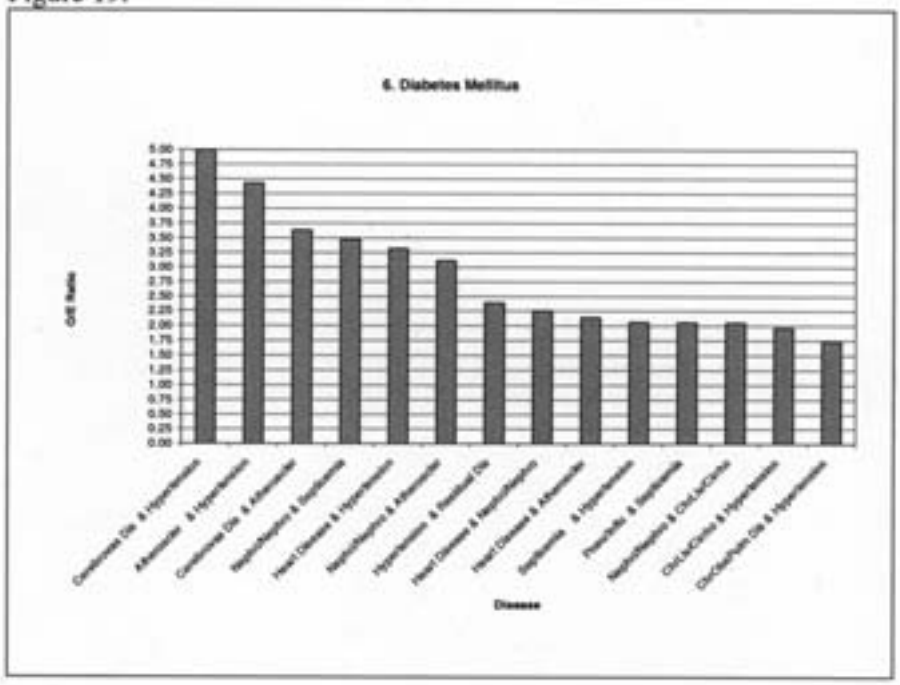


Figure 20.

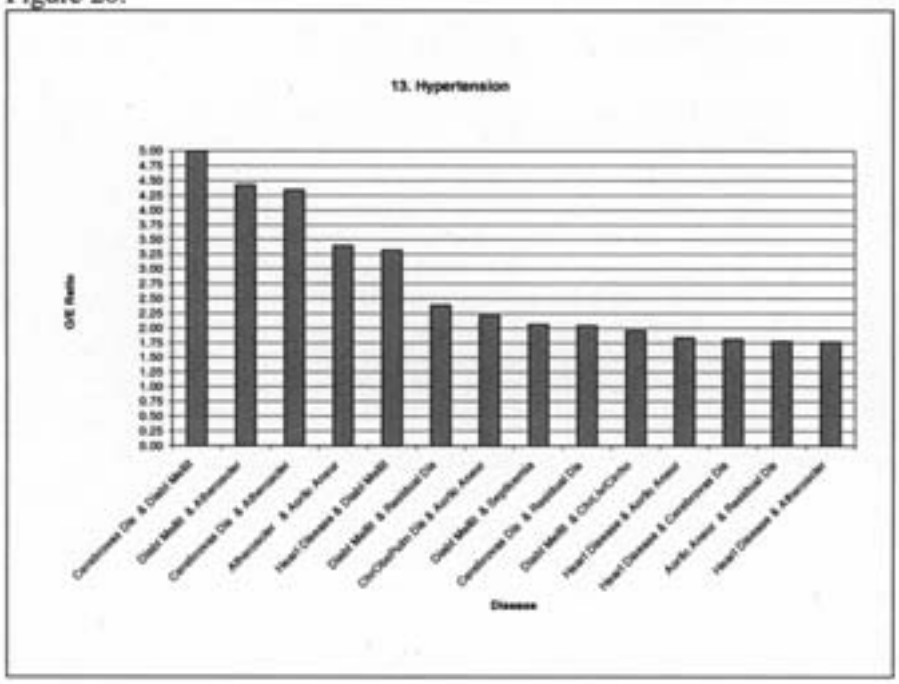


Figure 21.

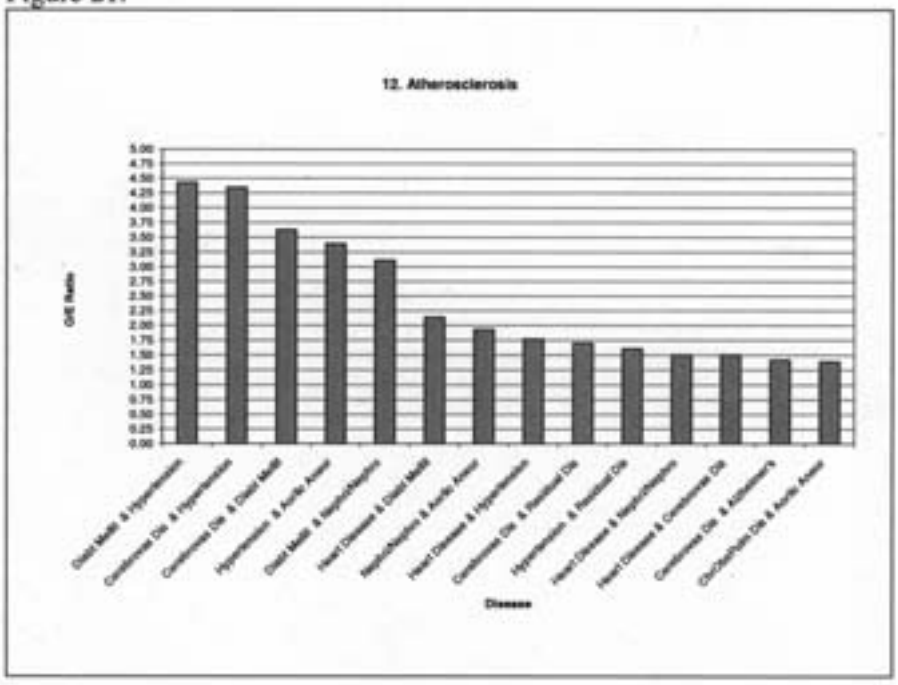


Figure 22.

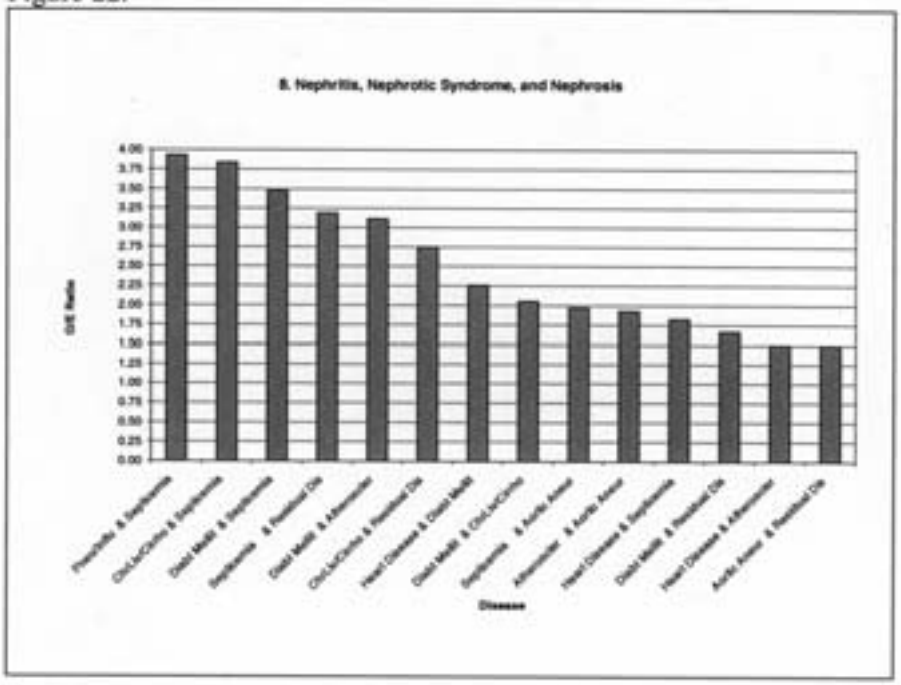


Figure 17 presents the top 14 ranked triples involving diseases of the heart. The highest ratio has disease of the heart combined with diabetes and hypertension, which occurs 3.3 times more frequently than expected under independence. This result convinces one that these three conditions are not independent. If these conditions were treated as independent in constructing cause-elimination life tables for these conditions, then the results in Figure 17 imply that the calculations would be incorrect. It may be difficult to assess how much error would occur in those calculations, but it is absolutely clear that some error would occur. The stronger the associations among sets of conditions, the larger would be the expected error.

Figure 18 indicates that the associations of cerebrovascular diseases with diabetes and hypertension yield observed/expected ratios 5.0 times higher than under independence, a big number. The next largest ratio (4.3) occurs for combinations of cerebrovascular diseases with atherosclerosis and hypertension, with the third largest (3.6) for combinations of cerebrovascular diseases with diabetes and atherosclerosis. Moreover, every single one of the associations shown in this figure has ratios significantly above 1.0.

Figure 19 displays the 14 top-ranked associations of diabetes with the other 14 conditions. All of the observed/expected ratios are significantly above 1.0. Figure 20 provides the corresponding results for hypertension, and Figure 21 does the same for atherosclerosis. The combination of diabetes, hypertension, and atherosclerosis has observed/expected ratios 4.4 times larger than expected under independence. Figure 22 provides corresponding results for the association of nephritis/nephrosis with the other 14 conditions. The results indicate that nephritis/nephrosis is associated with pneumonia/influenza and septicemia (3.9 ratio), and chronic liver disease and septicemia (3.8 ratio). Those appear to be very different mechanisms than the hypertension, cerebrovascular diseases, diabetes mechanism. The third-ranked association in Figure 22 (3.5 ratio), however, combines nephritis/nephrosis and septicemia with diabetes, indicating that the mechanisms may be linked through diabetes.

Discussion and Conclusion

Figure 23.

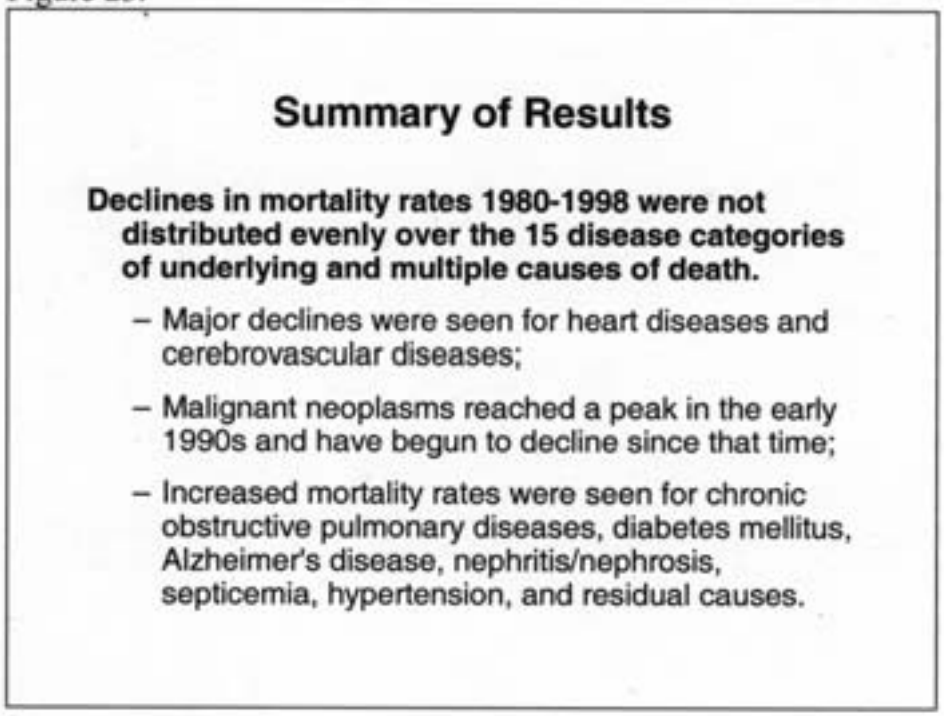


Figure 23 summarizes the temporal changes for the period 1980–1998 reported in the NAAJ paper referenced earlier. Declines in death rates were not distributed evenly over the 15 causes of death. Large declines were observed for diseases of the heart and cerebrovascular diseases; cancer death rates went up and then came back down; and increased death rates were observed for seven conditions: chronic obstructive pulmonary diseases, diabetes mellitus, Alzheimer's disease, nephritis/nephrosis, septicemia, hypertension, and residual causes.

Figure 24.

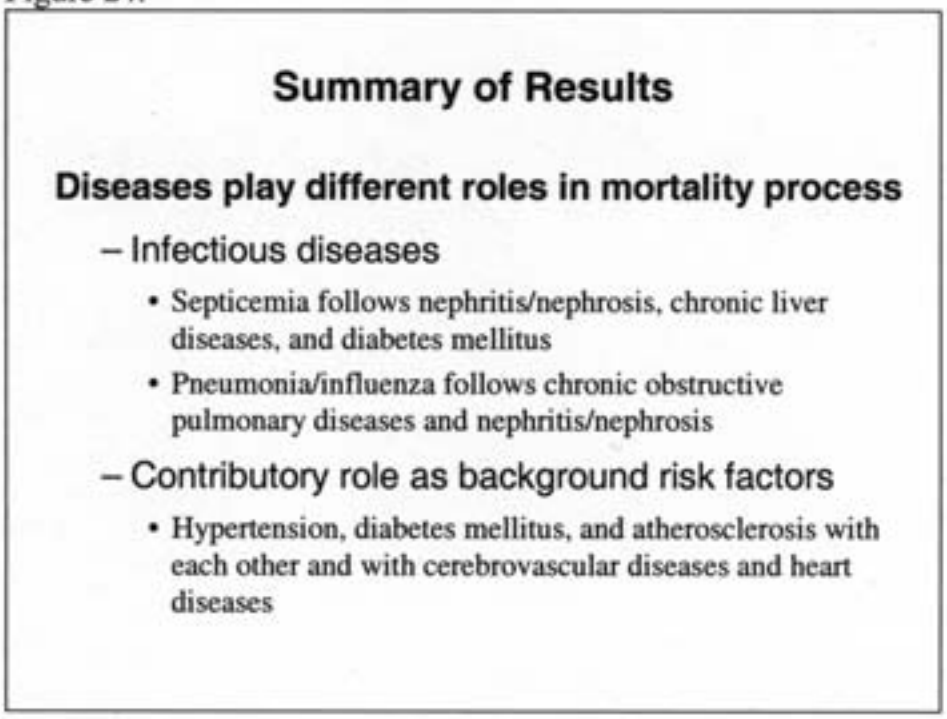


Figure 24 addresses the question: If diseases are not independent, then how does one interpret the associations? Two examples are provided, one for infectious diseases (where an infectious disease occurs as a consequence of another disease), and the second for diseases that serve contributory roles as background factors (which is a role that hypertension, diabetes, and atherosclerosis may serve in terms of their associations with cerebrovascular diseases and diseases of the heart). These examples are consistent with the format of the cause of death listings on Parts I and II of the death certificate.

Several comments can be made. I began working with multiple-cause-of-death mortality data 30 years ago, in 1973. I believe ours was the first nongovernmental research center to have access to the ACME files containing the 1.9 million records for all deaths in the United States in 1969. The challenge at that time was just to tabulate these data on the computer; they were so massive, computing resources so limited, and mainframe time so expensive. In preparing the NAAJ paper, I did an extensive literature search thinking that there ought to be thousands of articles on multiple-cause mortality. I was surprised how few articles had been written. Two reasons were offered to explain why so few analyses of multiple-cause mortality had been done:

(1) If the goal is to forecast total death counts or death rates, the argument was made that one could ignore causes of death, and related risk factors and lifestyle behaviors, because they are unnecessary. This argument was stated in the context of underlying causes of death; an even stronger argument could be made for ignoring multiple causes of death.

(2) Even if it was important to consider cause-of-death information, the multiple-cause-of-death data are so complex that it was not clear how one should proceed in analyzing and interpreting those data.

On the other hand, if the goal is to expand the scope of existing forecasting models to include population health status, then the multiple-cause mortality data should be of great value because these data provide unique information on end points of complex lifelong morbidity/mortality processes.

To understand the dynamics of such processes, one could integrate information from multiple-cause mortality data with relevant morbidity data, for example, from the National Health Interview Survey (NHIS),

the Health and Retirement Survey (HRS), or the National Long Term Care Survey (NLTCS). Each of these surveys collects health and morbidity information on living people. For example, the NLTCS collects health and disability data for a longitudinally followed sample of elderly Medicare enrollees. The NLTCS data are linked to Medicare billing records containing information on medical diagnoses and treatment procedures. Steps are underway to link the NLTCS to national multiple-cause-of-death mortality files. Similar mortality linkages have already been created for the NHIS (for persons interviewed in 1986–1994). As these and similar data sources and linkages are further developed, increasing amounts and additional types of information will be accessible for use in integrated models that can more accurately describe lifelong morbidity/mortality processes.

Such integrated models should provide understandable and coherent explanations of disease associations represented by observed/expected ratios of combinations of multiple-cause conditions that occur at levels one, two, three, four, or even five times larger than expected under the independence assumption. Moreover, such models should be structured to accommodate the reporting errors known to occur among the multiple-cause conditions reported on the death certificate. Creating such integrated models will be a major challenge for demographers, epidemiologists, gerontologists, statisticians, and actuaries. The research problems will be new and the progress will be exciting. The work, however, will not be simple.

Thank you.

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Discussion on Presentations of Session 2

E. JOUGLA: Eric Jougla from France. Firstly, I would like to thank Mr. Stallard for all the work that he has done in this paper. I have learned a lot from your books and articles. Considering that there are a lot of difficult things on which you focused regarding interpretation of biases, do you consider that we can actually publish basic tables for multiple causes of death, or do you think that this type of analysis must keep in the research field?

E. STALLARD: I have two responses: it is very easy to get very large tables, so with publishing—including Web-based publishing, I could envision a situation where you had a small number of readily accessible tables, even in printed form; with a Web-based mechanism for getting to more detailed tables. People with a specific interest, for example, in diabetes, ought to be able to follow links to obtain additional information on diabetes. With respect to what the summary tables would look like, I think one could take the top 15 or 20 causes. You would essentially double the size of the problem with each additional cause. Ten seemed to be too few; a lot of interesting results came up with the top ten. However, when we brought in atherosclerosis and hypertension we began to see some of the interesting results even though those were actually above number ten in the ranking. So I think it is important to go beyond ten, but I am not sure how far beyond. The totals that I described exemplify the types of things I would like to have looked at for this paper. Instead, my computer programmer spent several months manipulating these data. It would be great if there were a central manipulation of those data and those tabulations were available to everyone on a routine basis.

S. BAH: Would you suggest that this kind of exercise precede a construction of cause-elimination life tables or would you suggest we do away with cause-elimination life tables and concentrate on cause-dependency life tables?

E. STALLARD: I really feel ambivalent on that. I look at cause-elimination life tables, and at the same time, I say well, they are not perfect. The more you aggregate the causes before you do the elimination, the more you reduce some of the dependencies. It is probably the case that if you use those simply to identify a major public health problem and do not have a decision that is tied to the specific number, then you could be OK. If you say I absolutely have to have this number, and within four or five percent, then I would recommend that you investigate the dependency and begin to put some limits or bounds on that. I think those tables have to have a purpose; at the same time, the additional effort to model the dependencies would also be very helpful. If there is no dependency, then why do you want to reduce the risk factors for diabetes if it does not have a dependency with heart disease and stroke? The medical profession clearly recognizes that many of these conditions fall into syndromes, so you would like to have more than just a cautionary note at the bottom of each table.

L. GERAN: Leslie Geran from Canada. As I listened to all the panelists, it reminded me a lot of our efforts in Canada to train a user community of academics who were able to analyze our longitudinal health survey data. When we started, everybody just knew cross-sectional data, and they were unprepared; they did not have the skills or the tools or the computer programs that enabled them to analyze very complex survey data. So I would like to suggest to Roberto Becker when he talks about the need for a multiple-cause file that he needs to train the coders, have instruction materials, and develop a user community. We do not have one right now in Canada that is pushing us to get a multiple-cause file. I would love to produce one, but if it is not on the public policy list of priorities, then I have other things to do.

R. BECKER: I agree 100 percent.

R. LU: I have one question and one comment. I am a little bit confused about multiple-cause coding—the manual and training by NCHS. I am also interested in the ratio between the total mention of diabetes and number of underlying cause that varied from 1.80 in Brazil to 5.2 in Scotland. I can share our experience in Taiwan and compare it to that of Sweden: in Taiwan many physicians put diabetes in Part I of the death

certificate while in Sweden most of the physicians put it in Part II. I think that is the reason why there is a great variation between the ratios. So the similar question is about multiple-cause studies, namely that it is possible that physicians have different habits of writing causes of death or conditions on the death certificate. That also will affect our results.

C. ROONEY: In England and Wales we found that the number of causes per certificate went up throughout most of the second half of the last century but then actually started to fall again in the nineties. We also used to find that the number of conditions per certificate went up with age, but now there is hardly any variation across the ages. We used to interpret that as young people who died of one catastrophic illness or accident whereas elderly people accumulated diseases. But now it seems that actually even amongst the very young adults, they are actually only dying if they have several things wrong with them; so we are seeing certificates for people in their twenties who have had cystic fibrosis since birth and have a whole series of complications of that and also have diabetes or something. So the picture is changing a lot.

R. BECKER: About two months ago I presented in a PAHO (Pan American Health Organization) workshop factors that can influence the results of mortality analysis. It seems to me that one of the most important is how the data is certified.

C. ROONEY: Absolutely; we are going to have some other sessions in this meeting that are about training, including training doctors to fill in the certificate, because if they are writing junk, we will not get anything very good out of it.

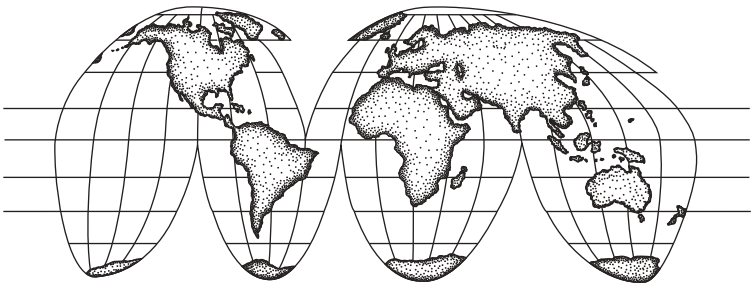
G. JOHNSON: I am Greg Johnson from Scotland. In relation to data for Scotland that was presented by Augusto Sanchez, we changed from three lines to four lines on the death certificate in 1999. An exercise following that began to look to see if there were any material changes in what was recorded by doctors. One of the points we did pick up was that diabetes started to be mentioned a little bit more. We thought that was quite interesting. At the time we introduced the fourth line, we also changed our notes and instructions to the doctors to complement the design of the certificates. We also included examples of what might go in Part II. Because we gave a specific example of diabetes, we think that may have actually resulted in the increase. The bad news was that there was some sort of artificial process going on, but the good news was that some of the doctors were reading the notes.

C. ROONEY: I think that the U.S. had a very similar experience a few years ago when they increased the number of lines on their death certificate. I think Donna Hoyert and Harry Rosenberg looked at similar things. In concluding, I have one last question to all of you. Could you take further the sorts of analyses that you have done, Eric [Stallard] if we had the kind of information that Roberto Becker and Ruy Laurenti would like us to have about the relationship of the conditions on the certificate? Do you think it would be useful to be able to sort out those other conditions that were associated with diabetes?

E. STALLARD: The short answer is we could use as much additional information as you provide, especially if it was reliable. The tables that I presented today did not use any of the cause-of-death ordering because they were based on ''record-axis'' multiple-cause codes, so they essentially throw away all of the Part I causal sequence. You get incredibly more complex when you try to put in the causal information. If you have an analysis where you do not use the causal information and then you run a similarly structured analysis where you do use the information, you must ask what new information have you learned and how does that revise whatever your original opinion was. This is like expecting that all the ratios (observed to expected) should be 1.0, and after converting the tables, finding that they are not 1.0. Consequently, we have to revise our opinion that conditions were close to being independent because the analysis says they are not. I could imagine supposing that the causal sequence is not important and then finding from an analysis that I was wrong. Thus, if diabetes is on Part I and heart disease is on Part II, for example, that may be very different from the case where we reverse it and put diabetes in Part II and heart disease in Part I, which may be a totally different disease mechanism.

SESSION 3

Electronic Death Registration



Session 3: Electronic Death Registration

Robert N. Anderson, Ph.D. (moderator), National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

This session on electronic death registration meshes well with automated coding of mortality statistics because of the potential that electronic death registration has to provide high-quality input into the automated systems. We are going to hear from representatives of three different countries: Lois Cook, who is representing England and Wales; Michael Coghlan from New South Wales in Australia; and Steve Schwartz, the Registrar of Vital Statistics for New York City in the U.S.

Electronic Death Registration in England and Wales

Lois Cook, Office for National Statistics (ONS), England and Wales

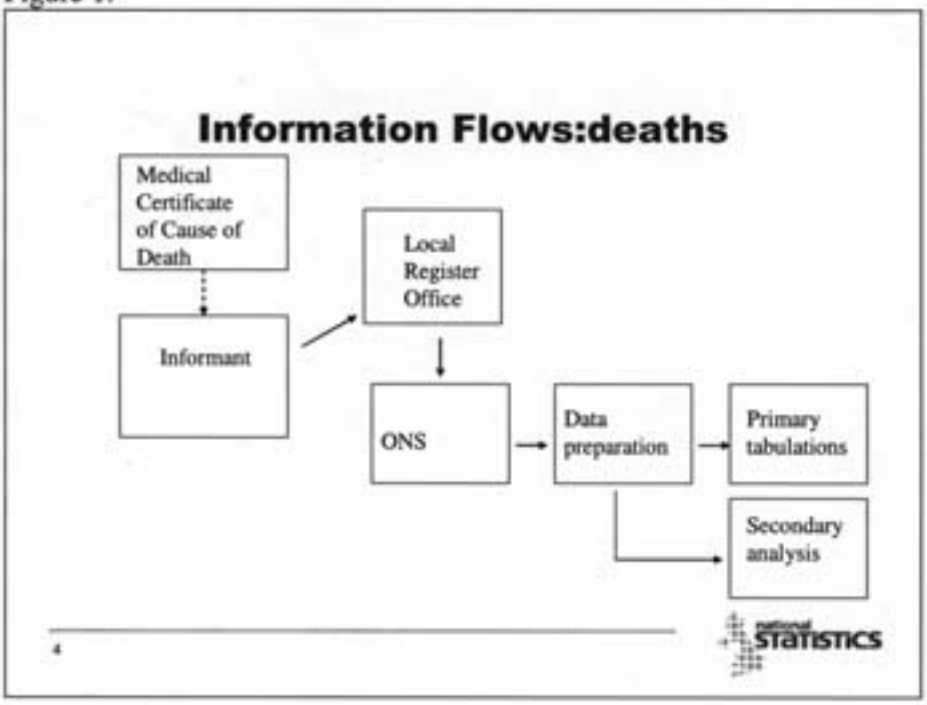
Thank you very much for your introduction and to the organizers for inviting us to Washington at cherry blossom time. I am talking to you today about electronic death registration in England and Wales. I shall give a brief introduction about how deaths are registered in England and Wales, about the developments of the electronic registration system, and about the challenges and opportunities facing mortality statistics as the whole of civil registration in England and Wales is being modernized.

I am just going to give you a very brief outline about civil registration system in England and Wales. Registration has largely been the same since 1837, with some piecemeal legislative developments to take account. The system in England and Wales is such that a death is registered by an informant in person at the local register office in the area where the event occurred. The information provided is legally prescribed, and the informant can be a relative or somebody present at the death. If, however, the death is being referred to the coroner as being unnatural, suspicious, or for other technical reasons by the certifying doctor, the coroner then would be the informant. There is a legal requirement to register, and deaths that have been certified by a doctor must be registered within 5 days. Most information in the registration system is provided by the informant. The registrar enters the data into the system but also onto a paper register.

Although I am talking today about electronic systems, most of the current system remains essentially paper-based. The medical cause-of-death certificate is on paper and is handwritten. The information that comes from the coroner, if the coroner is registering the death, is on paper although it is not always handwritten.

Figure 1 (below) is a simplified depiction of the information flows. There should be a dotted line between the medical cause of death and the informant because the medical cause-of-death certificate is completed by the doctor and given in a sealed envelope to the informant, who then takes it to the local registrar office. The registrar is a statutory officer paid by the local authorities who also provide the premises on which the registration office resides. The death is registered from information supplied by the informants and from the medical cause-of-death certificate. The information is entered into the system and written on the paper register. It is transferred either by floppy disk or through a secure Externet each week to the Office of National Statistics (ONS), where it is coded using automatic cause-coding software and prepared for analysis. Of the roughly 550,000 deaths in England and Wales per year, the vast majority is registered by the informants and the remainder by coroners after an inquest has been completed.

Figure 1.



In England and Wales, the data are used very quickly; 11 days after the end of a reference week, provisional estimates of the number of deaths registered in that week are published on the NCHS's Web site. We have a speedy system but not as speedy as that of Scotland.

The Registration Service Software (RSS), which was introduced in 1988, could be implemented without legislative change as the paper register is still the legal record. Implementation was placed on the 350 local authorities, who pay for hardware, software, and maintenance. Accordingly, the system specifications had to be simple and transparent, which had implications for the sophistication of the software.

The system had to include a facility for weekly extraction of data that could be sent to ONS. Because the system was developed in the late 1980's, floppy disks were chosen as the mode of transmission. The local registration system also had to integrate the ONS mainframe processing systems.

In 2000, the Registration Service Software (RSS) was upgraded because the old software was not year 2000 compliant. The RSS 2000 was an upgrade rather than a re-think of the registration software. Lotus Notes was used as the strategic tool since it is used in ONS for development. Floppy disks began to be replaced by a secure Externet, which is now used by about 100 out of the 350 offices.

The Registration Service tends to distinguish between information that is entered onto the paper register and information that is used for ''statistical purposes.'' I will quickly describe a few of the features of the system. The following relates to statistical information, which is not on the paper register. For the data fields we have online validation, data entry requirements, and online edit checks. For places, there are standardized place names. It is not possible to enter date of birth later than a date of death. For occupation, there are standardized lists that are developed locally. For cause of death, the registrar has a choice of whether to enter the cause-of-death data on the standard format or on an ''under 28 days'' format because we use WHO neonatal certificates. If the cause-of-death text is less than 75 characters, the registrar is presented with a part of a screen that has Parts I and II, the familiar WHO formats; if there are more than 75 characters, the registrar has a free-form version that accepts the cause-of-death text exactly as on the medical cause of death certificate with line numbers. The registrars can develop their own lists of often-used standard terms on the

cause-of-death fields. This was the ''statistical information'' that I was referring to earlier, the information that is not actually held on the paper register. Also, there are fields for the type of medical certificate, whether there was a doctor's postmortem (autopsy), and duration of illness. Duration of illness has a default of ''not stated'' but also has a series of standard terms available to the registrar, including acute or brief or chronic. The signature of the informant is not an electronic signature at this stage, but rather a statement that the informant has signed.

Among the legislative developments since 1837 were the Populations Statistics Acts of 1938 and 1960, which required information on the marital status of the deceased and, if married, the date of birth of the spouse. In 1938, this information was considered to be deeply confidential, never to be disclosed; stiff penalties were to be applied should those data be disclosed. On the Registration Service Software, a box reminds the registrar to explain to the informant that these data were collected under the Populations Statistics Acts. We also have a number of items that are voluntary, with a reminder to the registrar that these data items are voluntary.

The people who run registration software hold the view that there is a limit to the number of fields that can be validated at the time of registration and that the information that the informant says to be true has to be accepted as true. The other issue of concern is defaults on the system. I am going to take you through a case history and explain its problem for mortality statistics.

In England and Wales, one of the things currently occupying our time is inquiries and reviews. One is the shipment inquiry, and the other is the fundamental review of the coroner service. Both these inquiries and reviews were put in place after the conviction for murder of Dr. Harold Shipman, who was convicted of murdering 15 of his patients. The judges who adjudicated had some evidence that he had probably murdered more like 200 of his patients. Consequently, the whole of the death certification and registration process in England and Wales is under extreme scrutiny. There is intense interest in the whole of the process, in particular in the number of postmortems and who carries them out.

The Registration Service Software includes a field that asks the registrar the source of the medical information, whether the medical information comes from a doctors' medical certificate, a coroner's postmortem, a coroner's inquest, or whether the death is uncertified. This filter allows the presentation of the correct screen to record the data, either as it appears on the medical cause-of-death certificate or as it appears on the coroner's form. If either a coroner's postmortem or a coroner's inquest is selected, the field is changed to ''yes,'' meaning a postmortem. In a previous version of the software, the postmortem field defaulted to ''no,'' so the registrar had to actively indicate whether there had been a postmortem.

In the current system, it is impossible to record that a coroner held an inquest without a postmortem. The Home Office in England and Wales is a department that regulates the coroner service. Coroners are actually independent statutory offices, but the Home Office collects information about the coroner service. In 2001, the Home Office reported just over 1,100 inquests carried out without postmortem. The default system for a doctor's postmortem does not allow the registrar to override ''yes'' even if the coroner did not hold a postmortem. Therefore, it has not been possible for ONS to provide reliable figures on who does postmortems, which has been somewhat of a problem for us. This is an example of little problems of system specifications that can lead to large impacts on statistics.

I am now going to talk about the future changes to the Registration Service Software. In 1999, the General Register Office issued a consultation about modernizing the whole registration service. Modernization was driven in part by the need to continue with the electronic government agenda. The main changes concerned the organization of the registration service, but they will inevitably have an impact on the data collected at registration. The first document issued in 1999, called ''Modernizing a Vital Service,'' was looking for views from the public on a civil registration service that would respond to the needs of the individual, would continue to secure basic individual rights, and would be capable of adapting and evolving to meet changing registration needs.

The proposed changes include the facility to register in different ways, either over the Internet, by telephone, or in person, making it possible to register an event, or death in this case, anywhere in the country. The proposal is that a registration record would be created by the informants, possibly, if they have chosen to

use the Internet mode, online. It would be corroborated by a medical cause of death certificate in the case of deaths, which would either still be on paper or in the electronic medical cause-of-death certificate.

Another proposal is for a life record to be created for an individual that would gradually build up from birth through marriage. We are discussing whether divorce and death would be put into the life record. From a registration perspective, one of the main purposes is to prevent fraud regarding whether a person would be free to marry and to avoid a dead person's identity being assumed. It is not proposed to link, for example, a mother's record to all of her children. There is also a proposal to minimize paperwork among coroners, registrars, and doctors as a means of reducing delays in the system, although the delay in the registration system as far as coroners are concerned is not paperwork but the investigation of deaths.

What is proposed is not a wholesale change in the law, but the use of a legal framework designed to reduce burdensome regulations. All the proposals have to go out for public consultation for a 16-week period, and they are also subject to parliamentary scrutiny.

From a mortality statistics perspective, we want to collect additional information without adding a burden to the respondents; part of the rationale for the change is to decrease the burden on respondents and informants. One of the proposals is to collect information on ethnic group, which has been collected for the last two censuses. We are not proposing to change the medical cause-of-death certificate. While we had originally thought about proposing to add a fourth line in Part I, we are waiting for the Shipman inquiry and the coroner's review, which may result in wholesale changes. Although the potential is there to link to electronic certification, we are not proposing that at the moment.

We have been considering some issues for the impact on statistics. For example, if a person does register online, how do you ensure the authentication of the user (i.e., that the user or the informant is who they say they are)? We are accustomed to registrars guiding the informant through the system by explaining what the questions mean and, if they are distressed, helping them through the registration. With online registration, we have to think of ways to ensure that the registration is completed, and that the informant has not gone away to check a piece of information without coming back to the registration. We also have to think about the impact on statistics of how questions are asked for an online service compared to asking over the telephone or having a registrar continue to ask those questions.

We also have to explore the potential of linking to other data sources and how to ensure that the quality of other data sources that we might link to is good at a national level. We need also to think about how we are going to develop techniques and rules for dealing with conflicting information if the information from administrative systems is different from that provided by the informant for the same data item.

If we are proposing to link to other data sources, we have to look at the issue of consent, a very big issue at the moment in England and Wales. We have to make sure that if a person has opted out of having their records linked that this is recorded so that their records are not linked to those of the registration service. One of the improvements we will have from the proposals is the facility to pilot questions that we do not have at the moment, so we will be able to assess whether they will work. And we have to also think about the use of electronic registration to help informants understand what use is being made of their information when they register an event, that is, what use is being made of the information for statistical purposes.

The time scales for introducing the changes proposed in the civil registration review are hard to judge at this time. It is probable that any changes to the legislation governing civil registration will occur some time in 2005, and it is possible that a telephone mode of registration would be available some time after that. The proposals of linking to the death certification systems will possibly arise from the Shipman inquiry, which may require further legislation that is unlikely to begin to be implemented before 2006.

The changes proposed for the civil registration system offer us opportunities and challenges for the continuity and comparability of mortality statistics. I would welcome ideas and suggestions for taking maximum advantage of the opportunities that these provide for mortality statistics.

Thank you.

Advances in Electronic Registration: New South Wales

Michael Coghlan, Registry of Births Deaths & Marriages, Department of the Attorney General, New South Wales, Australia

I am going to talk about the e-services offered by the New South Wales Registry of Births, Deaths, and Marriages, which is the civil registration office for our state in Australia. In my position there, I have responsibility for registering all life events for our state, namely, births, deaths, marriages, name changes, adoptions, and moves. I have been with the organization for about 15 years. I was a coroner for about 4 years; that office in Australia entails an investigative role in terms of cause of death.

To give you a bit of history relative to civil registration in Australia is a document that has been circulated. It goes into some depth about the current position of civil registration in our state in New South Wales. In relation to the civil registration in Australia, the registry of births, deaths, and marriages commenced in 1956 in New South Wales. Prior to that, the responsibility in the established colonies was held generally by the churches. When we took over the registration function, a lot of those old records were transferred to our office. In Australia, interestingly, we have made the decision to have a closed registration system as opposed to many other countries. What that means is that you cannot obtain access to records of births for a period of 100 years, marriages for a period of 50 years, and deaths for a period of 30 years; that is part of our ongoing fraud strategy in terms of people having access to other people's identification. It is a very different perspective from that of many other countries in terms of civil registration.

Also as outlined in the handout, in recent times, we have made a lot of moves to coordinate the Australian states and territories in terms of consistent policy. We now have in place model legislation in all but one state, which will come on board shortly. That gives us a platform to establish common policies and activities across the jurisdictions. The registrars in each of the Australian jurisdictions meet quite regularly to establish new policies. They often have consultation meetings and work on issues before putting those into place in the separate jurisdictions.

I will talk specifically about the death registration service, which has been around now for about four years. We believe it was one of the earlier services in the world where we have the death registration information received by the registry from funeral directors or funeral homes in electronic format. Until now, the service has been voluntary for funeral homes to deliver the information through a secured Externet online. It is available in two formats, either as a Web version, where they access our Web site and key in the information record by record, or as a file, where they can enter a whole lot of information at a time and then download the file and submit it to us, which is more reliable but requires special software.

Until now, the penetration or the effect of that service has been that up to around 50 percent of our registrations come by the online service, which we believe is quite unique in the world. Unfortunately, interest to grow further has somewhat struggled, generally because of the industry itself, that is, the funeral directors from whom we require that information. As you might be aware, the funeral home industry is quite a traditional and conservative type of industry, and we have encountered some resistance to using technology, particularly the online service. The 50 percent of registrations that come through are largely from a smaller number of funeral directors who register a large number of funerals per year.

So we are taking another unique perspective. Under our legislation, the registrar has the ability to determine that the information is to be provided to our office in a form or manner decided by the registrar. We have now decided this year to exercise that portion of our legislation; from the first of January 2004, all funeral homes in New South Wales will be required to use the online service, with exemptions for certain categories of funeral homes. Those exemptions are quite limited in that they only cover specific remote areas of our state where there may not be any Internet service access or where the funeral home may be very small. Think, for example, of a small country town where the funeral director is also the local butcher or something else in the town, where they only record a small number of registrations per year, and where the economies of purchasing a computer and so on may be quite prohibitive. We have given the industry a 12-month lead-time notice of this change. We have also been working closely with the funeral director associations, and they have been quite supportive of our approach.

The main selling points of taking on the service as it always has been is that although funeral directors have 14 days to register an event with us in our state under our legislation, if they use the on-line system, our internal guarantee of service is 24 hours of registration. Further, the funeral director can order a death certificate from a vital statistics office online at the same time, and we guarantee to produce that within another 24 hours after the registration at the standard certificate fee. So, for example, if a death occurs on a Wednesday and a funeral is held the following Saturday, funeral directors are going back to their office, keying the information for us, and transmitting it to us. A staff member picks it up on Monday morning, registers the event, produces a certificate on Tuesday, and quite often provides the family with a certificate on Wednesday to use to finalize the estate. So there are very good customer service outcomes in relation to that.

Also, data quality has been an important driver for implementing the on-line service. The data fail requirements have very tight business rules in restricting the funeral directors who key the information. To clarify, the 50 percent that come in by paper have to be interpreted in terms of handwriting; that means it is double handling in terms of our staff re-keying the information. So with the on-line service we have seen a dramatic improvement in data quality in terms of input.

What about the future of our e-death service? We are looking at potentially 95 percent (or higher) usage of the service by the end of this year; in future years we will be encouraging those who have sought exemptions to use the service. We believe with the record uptake of the Internet and use of the Internet we should be able to achieve that within a reasonable time.

The medical certificate of cause of death that comes from physicians is currently still manually produced in our state; it is faxed to us by the funeral director at the same time that they electronically transmit the balance of the information. In that way, my staff members already take the latest registration information in the queue and seek out the fax copy that has come via the funeral director from the doctor to verify the cause-of-death information. Another project underway is an electronic medical certificate of cause of death. This is being developed with the health department of New South Wales. Distinctly in Australia, the vital statistics offices are separate in terms of being distant from the health departments and are also separate from the federal agency, the Australia Bureau of Statistics, to whom we provide the raw data on a regular basis. We need to move from that nexus of the three distinct areas to that of other parts of the world that are more streamlined or have more seamless transmission of information.

With the electronic medical certificate of cause of death, the Department of Health will be able to re-transmit cause of death to us on a real-time basis. That record, with a reference number released to the funeral director, will be matched up over night or in real time in the background. Thus, when my staff members take the registration information from a funeral home, they will have the electronic medical certificate of cause of death coming through at the same time. On a national basis, the Australian Medical Association (AMA) is supportive of this particular product because of the outcomes it will deliver in terms of improved data quality and improved service. We are hoping that all other Australian jurisdictions will also take on this service once we have piloted and tested it in New South Wales.

Among the benefits from the electronic services are strong customer service outcomes, as well as a quite beneficial administrative function. With funeral directors keying in the information, we do not need to use their out-sourcing bureau to re-key that information, which is a cost saving per record. Also, less human intervention on the part of my staff reduces internal labor costs. The Australian Bureau of Statistics (ABS) is a beneficiary, as well as other stakeholders such as the funeral home industry, which can assure their customers that they can deliver death certificates to them in quite a timely manner.

The paper death registration process, which accounts for half the records, takes around three weeks to register the information and produce a death certificate. So, a 48-hour turnaround time is quite significant for families who are trying to complete the estate.

The following is a nonexhaustive list of the current e-service projects that we have in place. The latest one we rolled out this year is the e-marriages service, where marriage celebrants in our state, in a similar fashion to the e-death service, can register the marriage event following the occurrence of that event. Again, we have a 48-hour turnaround time in terms of registration of marriages. As this is a newer service, we have used some more advanced planning in terms of the development of the interface. It even has time-of-business

rules in terms of what the marriage celebrant can enter into the interface. Of the 800 initial batch of registrations that have come through on the e-marriages service, we have only been able to detect two errors so far, which were brought to our attention after we issued the registry marriage certificate to the customer. Both were name errors that we would not have been able to detect through the normal business rules.

As a result of that success and the ongoing success of testing that particular service, we are now looking to use that as an automatic registration service so that my staff will no longer need to intervene before registering an event. There will be nothing else to check because the business rules in the automated system are so well-structured that we eliminated any errors before the celebrant was able to transmit that information to us.

The e-wills is another service we are considering whereby people can lodge and format electronically the location of their will in New South Wales so that future solicitors, the legal profession, and public trust offers can have us search our new database of the wills to see if that event has been registered with us. The e-verification services that we have in place, including the certificate of validation service, is a reverse validation service where a birth certificate, for example, is presented to a department of motor registration office to obtain a license or to register a vehicle. With a subscriber-based service, that office can check the validity of that certificate against our database. No extra information is supplied to that agency; it simply matches a number of set fields. Many agencies, including Passports Australia, the Department of Immigration, and the Australian Tax Office (the equivalent of the IRS in the U.S.) subscribe to this service to stamp out fraud in the use of registration of supply of funds or obtain other further identification.

In terms of the future, the New South Wales Registry is quite sold on the benefits of its e-services. We are looking to introduce the additional e-services that I highlighted earlier and enhance the ones that we currently have in place. To that end, we are looking at even eventually replacing our current e-deaths service with a more common platform that we could use for e-deaths, e-marriages, and e-births.

We are going to use the lessons that we have learned over the 4-year period with e-deaths to enhance the e-marriages service this year, expand e-services to births, and perhaps replace all of our services. We believe that it is quite an innovative approach, from which we have seen a lot of benefits. Those in our government to whom we report are quite happy with the approach we have taken and the progress we have made so far.

Thank you very much.

Automating 1947 Mortality Data REALLY FAST: The 1947 Smallpox Vaccination Campaign in New York City

Dr. Stephen Schwartz, New York City Department of Health and Mental Hygiene, New York, U.S.

Since this is a conference on automating mortality data, I want to tell you about a special project that happened just a week ago in New York City and has to do with the adverse effects that may be occurring from smallpox vaccinations.

As you may have heard, the United States, which is embarking on a smallpox vaccination program, has vaccinated about 25,000 or 30,000 people. As many as two deaths attributed to heart-related problems may have been caused by the smallpox vaccination, something that nobody had expected before. This would be a very high fatality rate with only around 30,000 vaccinations. The estimate before this had been about one death in a million vaccinations. Smallpox is a high-risk vaccine. Our Health Commissioner, Dr. Friedman in New York City, had a very clever idea.

In 1947, New York City had a smallpox outbreak with which were associated a total of 12 cases including two fatalities. Within a period of three weeks, New York City vaccinated five and a half million people. What an opportunity this presented for a natural experiment involving the mortality data from 1947! About a week ago, I got a phone call from my Commissioner asking if I had 1947 mortality data on computer. Well, almost; we had data from 1952 onward on the computer, but not 1947. We certainly had summary statistics, and it turned out we even had cause-of-death data by month for 1947. However, what he was looking for was actually by day so that we could try to relate the cause of the death to the smallpox vaccination campaign. On March 10th of 1947, the index patient died. By April 12th the city had administered half a million doses of vaccine; by May 2nd the city had 12 cases of smallpox, 2 deaths, and over 6 million people vaccinated.

What could we do about this? Did cardiac deaths increase? We developed a plan. We received that call from the Commissioner on a Friday and quickly obtained three years' worth of death certificates from our archives. Each year had 80,000 deaths; we received a quarter of a million death certificates, bound volumes, with the ICD–5 codes penciled in the margin of those paper death certificates. We also received 90 cartons of books that afternoon. The Health Department enlisted the aid of many volunteers, paid for overtime work, to do key entry. About 70 people worked 12-hour days on Saturday and Sunday keying in 81,000 death certificates with date of death, ICD–5 cause of death, age, race (actually in those days it was not called ''race;'' it was called ''color''), and sex. We completed this in little more than 2 days!

Stay tuned for the results; we are actually working on a paper that the Commissioner wants to submit by the end of this week. I have asked for the help of NCHS to determine the comparability from ICD–5 to ICD–10. So there it is, a very real world example of automating mortality statistics from 55 years ago!

Development of Model Requirements for an Electronic Death Registration System for Use by Registration Areas in the U.S. and Implications for New York City

Dr. Stephen Schwartz, New York City Department of Health and Mental Hygiene, New York, U.S.

First, I want to tell you what the concept of electronic death registration is in the United States; it is slightly different. We see it as a paperless Internet-based system that would have all of the participants participating electronically, excluding the informant, but including the funeral director, the medical examiner, the medical certifier, and the registrar so that it would be a paperless, Internet-based system. It would be timely; it would be secure; it would improve data quality with front-end edits and interactive queries; and it would meet standards of the National Center for Health Statistics (NCHS) and our association that represents all the states, called the National Association of Public Health Statistics and Information Systems (NAPHSIS). For example, we would want the physician medical certifier to complete the information not on paper but online. Those are the challenges.

New York City, for which I am the Registrar of Vital Statistics, is one of the 57 registration jurisdictions in the United States. It is not a State; it is independent of New York State and is relatively large, with a population of 8 million people and deaths numbering about 61,000 annually.

New York City tried to develop an electronic death registration system, but we were not successful the first time around. It turns out that a lot of other jurisdictions in the United States have not been either. What we are proposing is a relatively complex system, and it is a challenge to make a paperless electronic system work as well as our current registration system works today. New York City runs a death registration office that is open 24 hours per day. Funeral directors bring in the paper death certificate that has been completed by a physician within the legally required 72 hours from the time of death; this is typical in the United States. Upon receipt and acceptance of that paper death certificate, we date- and time-stamp it then assign a state file number to it. We issue the file number quickly because we require a burial or a disposition permit; the body does not go anywhere unless we say it can. Funeral directors bring in the certificate quickly; when they do, and upon proper payment, we issue certified copies on the spot 24 hours a day. We issue 95 percent of the certified copies of death certificates on the spot to the funeral director when he or she brings in the death certificates.

When we have talked to vendors about coming up with an electronic system, it is actually hard to do it faster than we do it today on paper. However, the funeral directors are really interested in electronic death registration because the burden on them is carrying the piece of paper to the single registration office in New York City. Even though we are a city, we are a large city with about 600 funeral homes. The busiest shift in our 24-hour day is not the normal business day but 4:00 p.m. to midnight. Why is that? Parking and traffic. That may not be an issue in New South Wales.

I am going to describe a national effort to develop model requirements, a set of national requirement specifications for electronic death registration, not the New York City model. Estimates these days for an electronic death registration system, if each state wanted to develop one, are over a million dollars a piece. If each state did it on its own, each state or jurisdiction would spend over a million dollars, plus the cost of human resources and time, and bear the risk that the system would not work. In short, it would require an enormous and redundant investment of resources. Consequently, the representatives of states conferred amongst ourselves and with NCHS; we asked why not actually try to develop a national model, because we hypothesized that we really are mostly the same. Now at a very high level of conceptualization, we could say everybody is the same, that is, you are born, you live, you die. Most of the countries work that way, right? We said that, too, but then in a large audience like this, California raised its hand and said ''most of the time.'' We had conjectured that we were 80 to 85 percent the same, yet there was California who said, ''Well, there are born-agains, and there is the afterlife.'' However, there are certain things that you do not include when you are building a national model.

Another reason for working together is that we can pool our resources and increase our success rate. The concept is as follows: we will share our expertise, and we will reduce our duplicative costs so that each state is not spending money on developing this. Again, it is money, it is technical resources, it is the time that each of us would have to spend if we did it on our own. And we are also sharing and reducing risks. These are all reasons for developing a national model.

In the lifecycle of a project, there are really three major phases. The first is the requirements, that is, the system requirements for an electronic death registration system. In this first phase of the national project, we are not developing the system design and data models, nor are we writing software or paying somebody to do it. The goal would be to have system requirements; the next phase would be system design, including the data model which includes edits and specific screen design. Finally, we would have somebody actually build the software.

The first phase is business needs, that is, defining the business needs and the functions common to all vital records operations. How would we do this? Some common functions that we were looking for and that we have defined so far are as follows:

- submitting a record for registration
- entering personal information
- entering medical data
- having a medical examiner take control of the case
- a physician signing the cause of death on the certificate,
- ordering certified copies

Each one of these is a whole business sequence, and each is essentially a heading for a business process.

What was our approach? The approach would vary by country. In the U.S., when we begin, we first decide to form a committee. That may not be the same around the world; some might decide to hire somebody like a consultant, or some might decide to have a bake sale to raise money. For us, it is to form a committee. So NAPHSIS and NCHS formed an oversight committee to help orchestrate this. Next, the bake sale: where were we going to have money to do this? The Social Security Administration (SSA), which pays death benefits and pays retirees an annuity in the U.S., has a very strong interest in finding out when someone dies, indeed, finding it out both accurately and really quickly. Each of the vital registration jurisdictions has a contract to inform SSA when someone has died. The contracts today say a state has to let SSA know within 90 days of the death, and even then the states say, ''You know, we are not really sure enough to give SSA authorization to terminate annuity benefits solely based on the death certificate because maybe the SSA number is wrong.'' Therefore, SSA has a really strong interest in getting fact-of-death information; they do not care why somebody died, but they want to know both quickly and accurately that somebody died.

Because the SSA has a strong interest in electronic death registration, it is offering to pay states to encourage them to build EDR systems. SSA's goal is to match the reported death with the Social Security Number (SSN) verified against SSA data files; in this way, SSA and vital registration offices are sure that there really is a match on SSN, date of birth, person's name, and sex. If every jurisdiction reported within 24 hours of the death or after receipt of the death by the State office, SSA estimates that it would save $55 million dollars per year, plus over a hundred person-years of labor (another $6 million approximately). So SSA would save over $60 million dollars every year if electronic death registration is able to deliver. Thus, SSA is anxious to get states to file electronically, though they do not care about cause of death; however, our partner NCHS does.

After we formed a committee, we created a couple of teams: a death workgroup to be hosted in New York City and funded by SSA, and a birth workgroup funded by NCHS. We hired a contractor to help us develop the national model. The national team hosted by New York City includes the States of Alabama, California, Florida, New York, and Washington, as well as representatives from NAPHSIS, NCHS, and SSA. The goal was to get a diversity of jurisdictions to develop a national model that would meet 80 to 85 percent of most of the States' needs. In addition to meeting most of a jurisdiction's needs, the components of the system should be modular, which means that one should be able to pick the components one wants. The

design should allow customization without actually changing the software; one should not have to hire a consultant, software firm, or vendor to change the software every time one wants to make a modification; certain things should be what the developers call ''configurable,'' so that one's staff should be able to make the changes through a table instead of hiring a vendor. Because New York City was hosting and actually building an electronic death registration system, the national model should meet New York City's specific needs for its electronic death registration system.

The approach we used to building a model is called ''use case modeling,'' which is a systematic approach to defining software requirements that describes the interactions between the users and the system. The most important thing is that the descriptions are unambiguous. Jurisdictions have found when they put out requests for proposals from vendors that the requirements were not unambiguous. If you tell someone to build a door, the vendor may build it three feet off the floor. What might seem obvious to the jurisdiction may not be that way for the vendor. When our first of several vendors built the system, we were concerned that in their demonstrations they were using examples of dead U.S. presidents. Well, that is OK except that we asked how the system could allow them to enter dead presidents from say the 1700s; we would expect an edit there. They responded that we had not specified that. Their system also allowed us to enter a date of February 31st because they similarly said we had not specified that we wanted calendar edits on days. If you tried to describe the door three feet off the floor, they would just say, ''Well, you did not say that either.''

One of the reasons for developing a national model is that each jurisdiction is not going to do the best job on its own developing specifications like that; however, getting together in a room until we are sick of seeing each other and putting all the specifications on paper can really help us come up with a solid model that a state can then use and modify for its needs.

The process we used was JAD, or Joint Application Development sessions that lasted three days each. We started out with a joint birth and death JAD session, and then there were four death JAD sessions, including one for the funeral director as the user to describe all the funeral director roles; another for the medical certifier or medical examiner/coroner role; a third for back office operations like registering a certificate, issuing certified copies, the accounting system, and point of sale; and finally, one for New York City's specific needs. There is also a joint birth/death JAD session starting tomorrow.

In addition to the 3-day JAD sessions that we had essentially every three weeks, our contractors developed a proprietary system software called an ''e-room,'' which essentially was an on-line chat room for collecting information from each of our team participants, storing that information, and recording the threads of discussion and development. We had weekly conference calls. We originally thought that we would solicit input from New York City funeral directors, the New York City medical examiner, and other New York City stakeholders, but we decided that the result would sound too much like New York City. Instead, after each session, we asked our team members to go back to their jurisdictions, talk to their stakeholders, then bring feedback to us. That was the model we used for stakeholder input. Finally, we had the oversight committee comprised of SSA, NCHS, and NAPHSIS state members.

What are the results? The jurisdictions really are similar, even in New York City and California, which was on our team. This is exceptionally good news. There are some variations among states since there is no Federal law mandating vital registration in the U.S. and each State has its own set of laws; however, the States have fairly similar laws and registration procedures. While there is not a single system that every State could simply buy and plug in, it is possible to build a national model that would meet most States' business needs and functions. Thus, it really is possible to create national model requirements for electronic death registration.

What are the next steps? The first is communication. The participants from half a dozen jurisdictions working on electronic death registration are very excited about it and motivated; they know exactly where our model came from. We have to sell it now to our colleagues in other states, which is not going to be easy because they may say, ''Wow, that sounds really good, but sorry we are doing our own, or we already started on this, or we do not quite see the applicability.'' It is really important to communicate with our colleagues and you with yours about the value of this project, its benefits, how it can be used, and its applicability to those jurisdictions. We are on a tight time schedule for two reasons: 1) One, there is a joint NAPHSIS/NCHS meeting, an annual meeting, coming up in early June in New York City, and we are going to be presenting our

results. The focus of this national meeting is going to be on vital record re-engineering. We are anxious to have both birth and death models ready for that early June meeting in New York. 2) SSA is going to come out with another round of requests for proposals encouraging states to build electronic death registration systems, and it wants to encourage states to apply the national model that we have developed to building their own systems. It would be a nice incentive for the States if SSA had as part of its evaluation of the systems a stipulation that the states use the national model.

Keep in mind though that everything we have done is only the first phase of the system, namely, the requirements phase. There is still system design, data models, and software development to be done. The plan now is to seek funding for the second phase of system design and creating data models.

Thank you very much.

Discussion on Presentations from Session 3

L. GERAN: Leslie Geran from Canada. I was on the Shipman inquiry Web site the other day, and I found it very comprehensive and very interesting for international comparison and development, especially when the Phase II results come out about how to improve death certification. Could you provide to the audience here the Shipman inquiry Web site address so we can all share in your benefits?

R. LAURENTI: Ruy Laurenti from San Paulo, Brazil. I appreciated very much these three presentations. Dr. Coghlan, in the New South Wales Registry, on page two you put birth, death, marriage, and change of name. Is the change of name due to marriage or divorce? My other question is why has the revenue from all certificates increased by 158 percent?

M. COGHLAN: The change-of-name function came to our office under our change legislation in 1995. Prior to that, the change name function was held by what we call the Lane Title's Office in our state, and that function was commonly known as the change by default. The reason for the change was to align that with the balance of the records that we maintain, providing a better ability to link it to our other databases of births and so on. The change of name serves effectively for people who want to vary their name for some legitimate reason. In Australia, we have a lot of recent immigration from people in Asian countries, and a lot of those people want to anglicize their names; others want to remove names for unfavorable reasons to avoid other people or for safety reasons. There is certainly no requirement for, I think, the example you gave for women to change their name following marriage. They can, by tradition, adopt their new married name and have a certified marriage certificate in evidence of the new name if they wish to select that of their husband. They will, of course, have their birth certificate indicating their original name or maiden name if that is what they prefer to use. In Australia, at least, agencies such as motor vehicle registry or passport agencies will accept either name. That is not one of the general reasons why people change their name. However, as I indicated, when we took over the function in 1995, we used to undertake about 5,000 changes per year; that doubled almost over night so that we currently do around 16,000. It became evident to us that some of the reasons for the change-of-name increases were for fraudulent purposes; people were changing their identity to obtain benefits from other federal government agencies for financial purposes and for other more devious concerns. Hence, we have tightened the requirements for change-of-name activity in terms of the identification that people are required to produce to us and the reasons for the change.

There are eight distinct jurisdictions in Australia, and as part of some of the joint arrangements we have, we make contact with each other in terms of advising any change of names to prevent shopping around by criminals in Australia. If someone changes their name 1 week in our office, they cannot go to the other side of the country to Perth and effect another change of name because my office would have advised the Australian and state offices that, although that person was born in this state, they have now changed their state. We have a common agreement that you can only change your name once in a 12-month period unless you have got very good reasons. Some people were changing their name every week before we brought in those stringent requirements, and you can make assumptions as to why that was occurring. Interestingly, most of the people who come to our country in terms of Asian backgrounds have settled in Sydney, and over half of our change-of-name customers are, in fact, people born overseas. Although we are conscious of tightening up the requirements for change-of-name activity, we have to also be conscious of not restricting that service to the people who are genuinely trying to use it.

Your second question is about picking out the statistics of our historical certificates sales, the Web site strategy that we put in place. We designed the Web site 3 or 4 years ago, and it has been quite beneficial. In fact, we receive around three million hits a month on our Web site and around one million page impressions a month. What we did was put out indexes, which is the basic registration information freely available on our Web site. Our second largest state in Australia, Victoria, just beat us to the punch and charges ten cents for every time we look at an index. We believe that would limit sales, so we have put them on for free, and you

can see the result of that in worldwide sales from people doing their family histories and applying for certificates like you do from a traditional work Web site like E-Bay, where you can order certificates online. We are seeing a huge sales increase as a result of that.

E. JOUGLA: I would like to know if there are some results comparing the amount of medical information with paper certificates and certificates written electronically. And I have a second question: do you think it is possible in the context of improvement of the certification to imagine an Internet-type system where the physician electronically completes the certificate?

M. COGHLAN: At this stage, we do not have an electronic transmission of medical certificate information. That is something that is being currently developed, but we are taking into account the usability of such a service not only to encourage medical practitioners to use the service but also for the benefits which we can obtain in terms of improving the data quality and not having to have a second human being interpret handwriting. We have options in terms of interactive displays but certainly not pick lists as cautioned by our statistics agency in Australia. There are certainly some benefits along those lines, which we obviously want to incorporate to make it as useful and as seamless as possible for that process.

S. SCHWARTZ: In the U.S. it is a fundamental requirement that we want physicians to use the system. Our goal is to have physicians directly use it and have edits up front so that if the cause of death listed is cardiac arrest, we want the system to say something like ''not so fast.''

M. COGHLAN: Certainly some of the lessons we have learned from our other e-services in terms of designing interfaces with very stringent business rules we can take into account to limit that sort of error occurring. What we are envisaging in the longer term with this sort of service is that physicians will be able to create or enter this sort of information from any place, for example, when they are sitting in their car park with their laptop, they can key in the information and then transmit that via their mobile phone to our office electronically. That is the sort of thing that we are trying to encourage. The initial stage is getting the public hospital system, which captures around 40 percent of the deaths in our state, as a stepping stone. The ultimate approach we are trying to take will be truly an electronic usable remote-type system that could be used anywhere.

PARTICIPANT: I have several questions because we are currently trying to do exactly the same exercise. In the case of England and Wales, I understood that you did not use digital signature. New York City, could you comment on that area, that element? My next question was how the medical information is reported in these electronic death certificates, as free text or diagnostic codes? What are your thoughts on that area? New York City, could you also answer that question? In Denmark, there is a joint effort to fill out the death certificate between several authorities: it could be the physician who takes a first look at the body, the funeral authorities, or even the police. Is it the same in your countries, and if so, how do you cope with that?

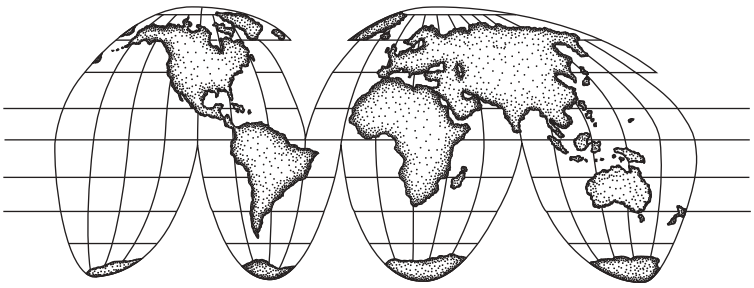
S. SCHWARTZ: As to the first question on authentication of the record, we have not arrived yet at a national standard, but New York City is leaning heavily towards a biometric device, which could be a fingerprint digital signature of some sort. We are really concerned to make sure that the person signing it is really the physician or the funeral director. Our certificates require two signatures, one from the funeral director and one from the physician or medical examiner. We really want to make sure that it is the physician and not the physician's secretary signing it.

In terms of cause of death, it would actually be the literal, so we do not want a pick list. The national standard is to have free text when filling out the certificate with the opportunity in an electronic system to have help screens and tutorials to help the physician to fill up his or her spare time reading those!

M. COGHLAN: Again, our approach is very similar to what is being proposed in the U.S. by the NAPHSIS organization for their design. In terms of the approach for that authentication, we try to look a little bit more broadly in terms of compliance and the source of information. We are looking at issues that relate to information that we have received from funeral directors without question for 150 years. The question that I am asking now is whether we should look at some sort of more stringent registration of funeral directors before they are able to lodge information with us, although there is some registration with health authorities for looking at health-type issues. We are now looking at an approach where funeral directors may have to come through some sort of authentication process up front, and then we can link that with various passwords and other options that are available. We are looking at getting in place some sort of platform that, although it will not recede from the current standard of security, will either match or slightly enhance that. We believe in putting the platform in place first and then working on other technology and available authentication strategies. Again, we can see if we can maintain at least the current standard and improve other outcomes such as data quality and customer service; that is possibly the best step to take rather than putting it off for longer and longer periods. It is best to start and learn from some lessons and then move forward from there.

SESSION 4

Language



Session 4: Language

Gérard Pavillon (moderator), National Institute of Health and Medical Research (INSERM), France

This session will be rather technical. We will have several presentations of different experiences beginning with a presentation by Donna Glenn on MICAR and SuperMICAR, the U.S. system from NCHS. We will then have a presentation by Monica Pace on the Italian approach, and a different approach by Lars Age Johansson on the Swedish system, MIKADO, and the problem of Entity Reference Numbers (ERNs). After that, two other presentations will follow: one by Moriyo Kimura on the Japanese system and finally, one by Casia Maria Buchalla on the Brazilian system. This is a set of very different presentations on very different systems on the same topic, which is the problem of coding. Because very often this topic is not well understood, I will try to make an introduction on the subject.

Introduction to the subject of language and automated systems for mortality coding

What is cause-of-death coding? We use only one word when, in fact, we may be talking about different things in mortality. We start with death certificates, and I consider only at this moment the cause-of-death information and some other individual data, such as date of birth, date of death, and sex, which are absolutely necessary for coding and editing. So we consider only cause-of-death information.

We start with death certificates and, at this point, we perform a ''coding function'' (I call it a ''function'' because at the end we get ICD codes). This is a first step. After that, from these magical ICD codes, we move on to perform what I call the ''selection function.'' It should be called ''Selection and Modification of the Underlying Cause Function,'' because it produces the underlying cause of death. These functions correspond to the SuperMICAR, MICAR, and ACME programs.

So when we speak of automated coding, we are talking about two things: 1) the coding, really coding, and 2) the selection of the underlying cause. Between the two, we have ICD codes. So the function that ACME performs, the selection of the underlying cause, is an international function because we use the common language of the ICD, and everyone knows this language.

If we are using one language, we have a coding function that is related to that language. If we have another language, we have another coding function that is different, because the language is different. So the selection of the underlying cause is what we call ''language independent,'' because the input to that function is the International Classification of Diseases (ICD).

The coding function is language dependent, just because the input is a text of the causes of death expressed in different languages. What we know and what we have to know is that the coding process can greatly influence selection of the underlying cause of death. So we have a process that is language-dependent, and this process influences the selection of the underlying cause.

Now, what are the coding difficulties? There are several. The first is having one diagnosis which may correspond with several codes. This is the main difficulty. For instance, if you mention on the death certificate a hemorrhage, how do you code that? Is it just a symptom or is it the result of the trauma? You have two possible codes. If you are coding in English, what is the code for metastatic cancer of the lung? You have two possibilities. Is it primary, or is it secondary? So it is more complex than we could imagine. When you have one diagnosis, the text of one disease, you cannot assign an ICD code each time. Sometimes, it is not as simple. We have another issue that is not always a difficulty, but sometimes it is: having one code corresponding to several diagnoses. This is not really a difficulty; it is a classification effect.

Another difficulty is that codes cannot always be directly assigned to each diagnosis expression. So we have to express the behavior of the code. For instance, you have a hemorrhage, so you have to check whether among the other diseases mentioned on the death certificates you have a violent death or trauma, an external cause. If not, you can then assume that the hemorrhage is a symptom. If yes, you can suppose it is an injury. But this is only a beginning, you see, because it gets more complicated. The external cause could even be the

result of the hemorrhage! Imagine that someone who is driving a car has an internal hemorrhage and has an accident and dies. This is a causal relationship where the hemorrhage is a cause of the accident. Suppose that someone who is driving a car has an accident and thus a hemorrhage. The hemorrhage is the effect of the violent death. So this matter can be complicated. You have to not just look at the relationships of the code but at the causal relationships between them.

So you have a death certificate, an index that identifies the disease, a behavior table and, at the end, you have an ICD code. Between the two, you are not really in the classification. So what can you use, Entity Reference Numbers? We have to use something that is not an ICD code yet but that is necessary to identify the disease.

The last problem is the difference between languages. For instance, you have a different expression of the same disease, myocardial infarction; in English, French, and Swedish you have different words. So you have different index, of course. It is obvious. You also have different meanings for similar expressions, and this is a problem. For instance, in English, metastatic cancer of the lung might be primary or secondary. In French, there is no problem. It is secondary, except that now we are moving toward the more English expressions and when we encounter the expression ''metastatic cancer of the stomach,'' it is primary—in French, I mean. So you see that depending on the languages, and even within the same language, you have different meanings for similar expressions, and this is a big problem. The behavioral table, and the behavior, is different in English and French for the same expression.

We also have differences in index size. For instance, in Swedish, we were working some years ago on a Eurostat project with Lars Age Johannson, who told me that there were 400 expressions for the same disease, pulmonary arteriosclerosis. In French, at the same time, we have only 100 expressions for I25.1. This means that there is not a one-to-one correspondence between two different languages. For some languages, there are possibilities to create similar, very numerous expressions. In other languages, that might not be the case. Thus, the index and the behavior table will be different depending on the language.

To conclude, the coding function is not simply an index. It is an index plus the behavioral code, the coding function influence, and the underlying code selection. We know that ACME is a standard for the selection function, the international one. How do we arrive at an international standard for the coding function? That is the challenge.

Thank you.

MICAR and SuperMICAR

Donna E. Glenn, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

We want to talk about language and what you need to do or could do to adapt the U.S. system to a non-English language. This year, I have to say, we finally got British English into the United States system.

ACME is the program that selects the underlying cause of death from all the multiple causes entered. The benefits are that it is ICD-based and, therefore, language independent. It is a consistent application of the WHO rules for coding underlying cause. However, it does require a specific set of multiple-cause codes; these are defined by our 2–B instruction manual that has close to 300 pages. In addition to that, the training for a productive, multiple-cause coder can take up to a year or even longer; one is investing a lot of time in training. Also, we estimate that it takes 1–1/2 multiple-cause coders for every underlying-cause coder. Thus, switching to ACME is not a cost savings.

MICAR (Mortality Medical Indexing and Classification), on the other hand, will make it easier to use the multiple-cause coding that goes into ACME. It uses Entity Reference Numbers. Entity Reference Numbers (ERNs) are six-digit numbers assigned by NCHS with no reference to a coding scheme at all. Each condition has one ERN. Acute myocardial infarction is number one. There is no reason for it to be number one; that is what NCHS assigned.

If start talking about converting our system, then you need to start with the very basics. MICAR 200 is a processing program. It uses ERNs. So if you can get to ERNs, you can use MICAR 200 without any kind of modification. The first thing you will have to look at is the dictionary, which is the backbone to the whole system for MICAR.

Two cautions: 1) I do not recommend that you convert every single word in that dictionary, which now has about 150,000 terms. We started out with 50,000 terms. We cannot tell you how much of that first dictionary was ever used. You can start by looking at your records and determining which conditions you need. 2) Do not do a literal interpretation. You want an interpretation in your own language that matches what the ERN is. You do not want to try word for word.

Start off by figuring out what the dictionary looks like. Before you start converting, please take the time to look at the dictionary. There are several sets of ERNs. The only ones that you need to look at to convert at all are those less than 200,000. The ERNs greater than 200,000 are what I call ''artificial.'' They are made-up ERNs based upon the application of a rule. You will never see them; they are totally internal to the system. So if you want to know what they mean in your language, you can look at them; as far as doing a processing system, you do not need them.

I will give you an example of how artificial Entity Reference Numbers are used. If it says on the death certificate, ''grand negative septicemia,'' then the system's default code is going to be Entity Reference Number 348 with an ICD–10 code of A415. Once MICAR 200 starts processing, the first thing it is going to look at is the demographic variable of age. The age, on this record, we are going to say is less than 28 days. Internally, that entity reference number 348 converts to 202,982. Immediately, you know it is artificial because it begins with a number greater than 200,000. The term that is equivalent to it now is ''newborn grand negative septicemia,'' and the ICD code will also change from A415 to P368, which is a ''baby'' code.

We also say that we have one ERN for each term, but that term can be reported in many different ways. With acute myocardial infarction, ''AMI'' is the standard abbreviation. It could also be ''acute myocardial infarc or ''acute MI.'' Those are considered aliases, which are stored in our dictionary as aliases. If you ask us for the dictionary, you get it with the term ''acute myocardial infarction'' assigned to ERN 1 and all the basic flags. A separate dictionary pulls the aliases for you. If you are doing a conversion to your language or a translation, you may not need all those terms. Some of them we put in to help SuperMICAR, which takes literal text and needs some help sometimes.

The next thing that is important is the order of the words in the dictionary. We have a standard order, with acute or chronic first, followed by adjectives or modifiers, followed by body site, and then the lead term.

We did this to help with teaching. Our coders had entered the terms for the MICAR dictionary. We also based it on the way we see information reported on death certificates in the U.S. This order may not be good for you in your language, but I do suggest that you find a standard order of the words, which will make everything easier.

If you choose to work with the MICAR dictionary, it carries four important flags. Three of the flags are absolutely necessary for MICAR 200, but they are not important when you translate. The program itself has this information, but it may help you decide which term you want to equate to one of our dictionary terms.

The first flag is what we call an N and an E, which is a term that applies both cause and effect as opposed to a term that is just an injury or a term that is just external cause. Use it to help decide what is equal.

The next two flags deal with cancers. We do our processing by cancer list. We can define for you which list we have put each cancer in. Another part of cancer processing needs to know the anatomical site or the histologic code. That is built into the dictionary. Those can help you, but you do not need to carry them.

The fourth flag is what we call our ''drop-word flag.'' As you know, many times the death certificate will have information that is not important for the classification, like ''primary'' or ''probably.'' There are times when you do not need these words. The system is designed to drop them and still match the dictionary. However, there are times you cannot drop them. If you have a neoplasm, you cannot drop the word ''primary.'' So that flag is set to say if, after you drop a word, you match a certain code; if this is a neoplasm, then you must go back and reject the initial term because we do not have it with the word ''primary,'' and we cannot let it pass.

Once you have your dictionary converted, you need a program or a system to collect the data and process it to turn the literal information into Entity Reference Numbers. We have two separate programs, PC-MICAR and SuperMICAR. They both have the three following functions: 1) an interactive spelling checker; 2) a way to drop extraneous words; and 3) a way to do singles and to make plural terms singular.

PC-MICAR requires a trained coder who puts the terms from the death certificate into the standardized or sanitized fashion. This means that PC-MICAR is a much simpler program to work with. It is basically a ''look-up.'' Beginning with 2003, we no longer use PC-MICAR in the U.S. We were not able to convert the training package, so we have now dropped it completely. Consequently, we are totally dependent on SuperMICAR.

SuperMICAR is an enhanced version of PC-MICAR. SuperMICAR's main purpose is to allow actual literal entry of what is on the death certificate with minimal training of the data-entry staff. We have found that the training very much needed is in medical terminology and anatomy, not intrinsically, but because it helps with interpreting the doctors' handwriting.

I am not going into a lot of detail on SuperMICAR conversion because we have covered it in other ICE meetings. I can discuss it with you if you would like to find out what properties it uses. SuperMICAR probably requires a more skilled programmer than PC-MICAR. PC-MICAR, by the way, was originally written in Dbase 3, which is extremely easy programming.

To summarize the steps required to translate the MICAR system into a language that would result in Entity Reference Numbers for processing:

1) Convert the MICAR dictionary, but not totally, for what you need in your dictionary.
2) Convert drop words or synonyms. There are some other minor tables attached to them that are all language related. You would have to decide whether you want or need to convert them.
3) Convert the lexicon, which is used for spelling, because your spelling is going to be different from English spelling.
4) Translate the external prompts. I chose not to discuss that term because I think I could spend a half an hour explaining how we do external cause. I will save that for another day.
5) Convert the program code.

PC-MICAR is the easiest, and it has less English language in it. SuperMICAR has embedded English, so it is going to be more difficult to take SuperMICAR and convert it or translate it into another language. In

addition, SuperMICAR has at least two extra tables that you have to use. One is a word dictionary, and it relates to the standardized order of the words. Every word is defined by what order it would be in when we come up with a standardized term. That dictionary would have to be converted. And then there is one other dictionary of about 600 words of specific rules dealing with those words. Those words will not be the same in another language, so you would want to look at those rules and maybe come up with your own special way of handling that.

In conclusion, I recommend that you base your translation on the principles of the MICAR dictionary and the principles of SuperMICAR or PC-MICAR, not a literal translation, but by principle. We can give you the materials that we use with MICAR 200, which will simplify ACME tremendously.

Thank you.

Linguistic Issues Concerning the Use of ERNs in Italy: Problems, Perspectives and a DB for BBD

Monica Pace (presenter), Stefano Marchetti, Paola Giorgetti, Francesco Grippo, and Luisa Frova, Causes of Death Unit, Department of Social Statistics, Italian National Institute of Statistics (ISTAT), Italy

My presentation deals with the current status of the ICD–10 automatic coding implementation in Italy. ISTAT has been using the ICD–9 MICAR and ACME system for deaths since 1995. For that task, an Italian dictionary was translated from the U.S. one and adapted to our language. We are now facing the change of revision and all the related problems with the dictionary.

Our dictionary (defined from now on: BBD-9 ITA) was created according to the following criteria:

- Translated by a single physician;
- Highly dependent on ICD–9 because Italian-specific terminology was often introduced with compatibility to the final ICD–9 code. At the time, this appeared as the simplest strategy, but now it shows all its limitations;
- No spaces between words;
- 187,000 terms;
- Not substantially updated since its first release in 1998 due to human resources limitations;
- Different Entity Reference Numbers (ERNs) have different levels of accuracy when translated into Italian; in fact the best accuracy was given to the most used ERNs.

Among several possible examples, let me show you some of the problems we are currently facing in updating and improving this dictionary. The use of automatic translation of single words has created some problems such as for the term ''malformation'' (ERN in BBD10 ENG: 092401). The meaning has not been maintained and has completely changed in Italian because ''mal'' is the abbreviation for ''malignant,'' and ''malignant formation'' is a synonym of ''malignancy.''

Another example is the abbreviation for diabetes ''DI'' (ERN in BBD10 ENG: 000060). The problem here is that ''DI'' means also ''OF,'' so it is impractical for us to consider this preposition as a drop word because we would miss cases of diabetes; on the other hand, we may sometimes obtain very bad results with the automatic translation procedure because when the word ''DI'' (intended as ''OF'') is entered, the risk is to see a code for diabetes appearing on the certificate.

Another example is for ''arteriosclerosis'' (ERN in BBD10 ENG: 000008). This term is defined by two aliases in English, while in Italian we have 234 aliases for it, some of which are very complex and include several sites because Italian physicians have this habit. The medical term ''*aortomiocardiocerebrosclerosi*'' includes a description of multiple sites; we are now considering the possibility to split it and deal with it in a more accurate way in BBD10 ITA, by assigning a different ERN for each site instead of considering the term as ''arteriosclerosis'' as we do now.

The last example deals with the term ''malignancy'' (ERN in BBD10 ENG: 011641), which has one alias in BBD10 ENG. There are 154 aliases for this term in BBD9 ITA, some of which are shown in Table 1.

Table 1. Some Italian aliases reported in BBD9 ITA for the English term "malignancy."

DISCARIOCINESI
T
K A PARTENZA IGNOTA
NEOFORMAZIONE PRIMITIVA IGNOTA
CANCRO AD INSORGENZA SCONOSCIUTA
KREBS DI ORIGINE SCONOSCIUTA
NEOPLASIA MAL
NEOFORMAZIONE MAL
TUMORE PRIMARIO IGNOTO
ETEROPLASIA ORIGINE SCONOSCIUTA

Let me make the two most relevant considerations on this. First, we use several different words to describe a general malignancy, including tumor. For us, ''tumor'' is usually malignant unless stated as ''benign,'' and this poses some additional problems when dealing with a dictionary derived from a different language. Second, I would like to emphasize that 6 lines out of 10 shown in Table 1 include the definition ''primary site(s) unknown'' or analogies. This means that at the present time we have a redundant dictionary which needs a better parsing strategy to be implemented in future versions. Keeping the above-mentioned problems in mind, we defined the aims for the BBD10 ITA implementation as shown in the following points:

- To translate the pathologies and not the single words because we already have part of this work done;
- To use the translation done in the past as a background to maintain comparability and good use of Italian medical terminology;
- To eliminate redundancies by a better management of parsing (synonyms, drop words, etc.);
- To improve specificity also in cases of complex strings;
- To obtain a flexible and reliable product by a shared, verifiable and easy-to-update strategy.

In addition, we had these goals concerning BBD10 ITA; it had to be:

- ***shared*** among all the operators by means of a decision tree upon which there is general agreement. It took a lot of effort to come out with common decisions on how to deal with different problems and how to define a flow chart for each category of decision that could be taken; once developed, this tool guarantees the ''internal quality control'' for the BBD10 ITA construction;
- ***verifiable*** by the use of different flags placed on each translation—both for operator and level of quality of translation (certain, doubt, compatible only at ICD–10 level, cannot translate)—and finally revised by a highly skilled person. This approach should keep memory of any step because one of the problems we have with BBD9 ITA is that one person decided what to do, but in several cases we have no records of the criteria that were followed;
- ***easy to update*** because of specifically designed DB structure and tools in order to take into account future periodic changes in ICD revisions and ACS improvements. We must not forget that ICD–10 philosophy has changed and its updating mechanism is expected to be speeded up with respect to the past. For this reason, the updating and the maintenance of dictionaries is of growing importance according to ICD modifications.

These goals can be obtained by means of a database (DB). For this reason, we developed a database for BBD management in Oracle 8.0. The DB contains the following files:

- BBD9 ITA
- BBD9 ENG
- BBD10 ENG
- ERN ITA (9th revision)
- ERN ENG (10th revision)
- Italian ICD–9 and ICD–10 text with notes.

From the user standpoint, the search in the DB can be done either by Entity Reference Number, fluent text, or ICD code; in any of these cases the link to ERNs or ICD code is given, if needed.

In the translation front page, the ERNs with the corresponding English term are shown. By clicking the ERN, the Italian aliases in BBD9 ITA for that ERN are shown. The translator can choose to modify the Italian text for that string and/or decide to change the assigned ERN by further clicks. Then a flag must be assigned (including ''cannot translate'') to keep track of which kind of decision has been taken for each string, as described before. Any translation can be modified from the translators themselves or from the reviser.

I am not going to show you everything, but we think this is a flexible tool that can be adapted to different situations and needs. If you are interested in going into details, you are welcome to contact me.

Thank you very much for your attention.

Building the Swedish Dictionary— The Importance of Language Standardization and Experiences of Using ERNs with a Non-English Language

Lars Age Johansson, Board of Health and Welfare, Sweden

I am going to tell you of some of the Swedish experiences in developing and maintaining our dictionary. What seems to be unique for the Swedish coding system is that we do not use the Entity Reference Numbers. We tried another approach to the problem of assigning the correct ICD code to the expressions on the death certificates. To try and make this clear, I will describe the entire process of building a dictionary.

When you start developing a coding software, you have to identify the terms you wish to include in your dictionary. Somewhere, you have to find and capture the terms. You will very soon find that you cannot put everything into the dictionary that the doctors happen to put on the death certificate. You have to standardize their ways of expression in some way or another, popularly referred to as ''parsing.'' You clean the text in some way or another.

You will also discover that you need tools for grouping expressions. Say that somebody decides to change the coding instructions for myocardial infarction. As Gérard Pavillon reported, we had in our Swedish ICD–9 dictionary 400 different expressions for myocardial infarction. So, obviously, we need an efficient way of finding all those 400 expressions and to make changes to all of them simultaneously.

So I shall start with the data capture. We have basically three different sets of medical terminology in Sweden. First, we still encounter classical Latin and Greek, like ''*neoplasma malignum hepatis cum metastasibus pulmonum*,'' which means malignant neoplasm of liver with metastases of lung. That is disappearing. We had more of it 10 or 15 years ago. It is being replaced by Swedish terms based on Latin and Greek, basically the same as you have in English, ''malignant neoplasm,'' for example.

The problem is that we now have at least three different ways of spelling those Latin- and Greek-based Swedish terms. We have British spelling and American spelling because of the kinds of textbooks that our physicians use during their training. We also have German-Latin spelling because up to the Second World War, Swedish physicians were trained with German textbooks. Finally, we have vernaculars, which are medical terms not based on Latin and Greek. I suppose an English equivalent would be ''smallpox.'' Such terms are quite common in Swedish.

I was very interested to hear that in Italian you can easily make long compounds, which is very easy to do in Germanic languages as well. You can pile word upon word upon word, and you can combine the words in any order you like. There are no hyphens, blanks, or connecting particles, yet the coding system still has to deal with that.

The advice we received when we started was simply to scan the pages of some useful medical dictionary, and also add the terms of the ICD alphabetical index to the coding system. We tried, and I think we got a match rate of about 1 or 2 percent. The explanation is, of course, that very few doctors use the terminology that they are supposed to use, so we decided rather to capture terms from actual death certificates.

Next, we took a sample of 10,000 death certificates. The expressions we found there did not make us happier because when we made a frequency count, we found that over 30,000 of those expressions were used only once. This is due partly to the possibility of making new compounds and partly to lots of minor differences in spelling. Thus, we realized that we really needed a very efficient parsing module in our coding system.

We spent, I would say, about two or three years developing the parsing module of the MIKADO. We took much from a Canadian coding system called the ACTR, which was developed to code variables from the census. We developed a set of tables that would control the parsing. Each table would take care of one of the stages in the process. We have tables to handle blanks, hyphens, drop words, synonyms, substitutions, exceptions, etc.

We also developed a way to keep in the system memory some of the information that we had deleted from a string, to allow it to influence the selection of the ICD code, for instance, phrases like, ''this disease

was complicated by.'' If you have that mentioned in Part I of the death certificate, it means that one of the codes should be moved to the line below the other one. I think we succeeded fairly well in developing this standardization procedure because if we run a batch of death certificates without the standardization, we get a dictionary match in about 40 percent of cases. If we switch the standardization module on, we get a match in about 90 percent of cases. A drawback is that the standardization procedure is very complicated. We have nine tables to govern the procedure, with almost 3,000 lines of individual instructions. This means that maintenance is considerable.

Now, how do we maintain the dictionary, and how do we group the expressions and ICD codes? As pointed out earlier, we have all kinds of terms in all thinkable parts of the alphabet, which all go to the same ICD code and which should be handled in the same way by the coding system. So we clearly need to group them. There are also cases in which expressions coded to different ICD codes are handled in the same way or should be handled in the same way. For example, many terms could, under certain circumstances, be interpreted as complications of surgery. So you would need a tool to find all of them, regardless of the ICD code, and to implement a coding change to all of them at the same time and in the same way.

We can start with the grouping of dictionary terms. The obvious thing to do would seem to group by ICD code. That would make dictionary maintenance quite easy. The problem is that several ICD codes contain a mix of conditions. They are not always similar and sometimes should be treated differently by the coding system. Also, if we use the ICD codes, we cannot use the MICAR Decision Tables, which would very much facilitate the procedure of selecting the correct multiple code for the ACME input. Of course, as Donna said, the instructions for how to correctly code a death certificate with multiple codes are fairly complicated.

At first, we tried to use the Entity Reference Number. If we could assign Entity Reference Numbers to our Swedish terms, we would not have to think of the code modifications. The MICAR system would take care of that for us. We tried in Sweden to implement the Entity Reference Numbers in 1994, but that was not easy, we found. We did not really understand the structure of the Entity Reference Numbers; there just seemed to be no connection between the ICD code and the Entity Reference Number, and that made it very difficult to memorize the codes. We also found it difficult to match Swedish terms to Entity Reference Numbers; in some cases, where there was a match of terms, we found, as in Italy, that the terms were used in different senses.

Let us start with the difficulty of memorizing the Entity Reference Numbers. Myocardial infarction is quite easy to remember since that is number one. Other ones—acute lymphocytic leukemia is 58–052, not to be confused with acute myelocytic leukemia, which is 15–709—are really not that easy. So when you work through a dictionary in another language and try to match Entity Reference Numbers, you have to look them up each single time, which is rather time consuming.

You could use abbreviations, if you like, but some of those abbreviations are very similar to others and you could end up with the wrong term. We tried to do it anyway, so we developed a kind of software to match Swedish terms to the nearest equivalent English term. We found that for about 50 percent of the terms we did not get an equivalent because our terms were based on vernacular Swedish, and they did not match any English expressions. For each one of them we would have had to look through the ERN dictionary to find the closest match. If there was no very close match, we would have to create a new Entity Reference Number. As I said, we also found differences in what medical terms actually mean in Swedish in contrast to English.

In conclusion, we found that the Entity Reference Numbers are not language independent. You have to evaluate each single Entity Reference Number before you assign it to an expression in a non-English language. That would take more time than to try to copy the instructions from Manual 2–B for multiple-cause coding into our software.

We finally decided to stick to the ICD code, and we grouped our medical terms by the ICD code. To take care of groups of expressions, we developed a kind of coding matrix that consists of an ICD code plus the standard medical term for that ICD code. For that matrix we would enter all the code modifications necessary, as specified in Volume 2–B, and the software would automatically copy those modifications to all other terms with the same ICD code. However, that does not always work because some ICD codes contain a mix of

conditions, and perhaps the instructions only apply to some of them. In those cases, we would subdivide the ICD codes into subgroups that could be treated differently. There is also a possibility to enter exceptions into our dictionary.

Through this strategy of having an efficient language-parsing procedure and grouping on ICD code, we managed to keep the dictionary reasonably compact. The Swedish dictionary has only 7,000 terms. The small size allows you to have a fair overview of the contents of the dictionary, but thanks to the parsing module, the software still codes about 90 percent of the terms we encounter on the death certificates. Had we known about the Entity Reference Numbers ten years ago when we started developing the Swedish dictionary, we might have chosen a somewhat different approach. I still think that we would have tried to go by ICD code rather than by ERNs, but we would have checked our code modifications very carefully against the ERN dictionary.

Thank you very much.

Automation System on Mortality in Japan

Moriyo Kimura, MD, MPH, Ministry of Health, Labor and Welfare, Japan; Hibiki Ueda, BA; Kazuko Takemura; Hiromi Takeuchi, MD, PhD; Ryuji Agematsu, MD; Kishio Ono, MD; Haruya Iwamoto, MD; Tetsuya Tamura, PhD.

Background

Japan introduced the new automation system upon adopting ICD–10 in 1995. The new system called ACSEL, an acronym for ''Automated Coding of Diagnostic Expressions and Selection of Underlying Cause of Death,'' has the basic structure of the MICAR-ACME system with Japanese original rules and modifications. ACSEL has roughly four steps: (1) data editing/cleaning, (2) Phase I, (3) Phase II, and (4) result output. In this session, Phase I and Phase II processes are discussed.

Phase I

This phase is to assign ICD–10 codes to every cause of death (COD). Since we use four different types of characters (Chinese, Hiragana, Katakana, and Alphabet), enormous combinations of medical terms for one ICD code exists. Under ICD–9 auto-coding system, we used ''exact matching procedure.'' There were 4,310 variations in the ICD–9 dictionary that can be accepted in order that the terms were converted to ICD codes. Even with tiny differences, the terms were rejected as non-matched. Since there was no recovery system, all rejected terms had to be coded manually, and the workload of medical coders was substantial. One of the major goals of ACSEL was to ameliorate the situation. The flow of Phase I and each step are described as follows:

1) Editing: ACSEL edits terms according to a standardized procedure.
2) Element extraction: As MICAR generates the multiple-cause ICD codes, Phase I is for applying ICD–10 codes to every reported cause. ACSEL separates causes into ''elements,'' which are 6-digit numbers similar to Entity Reference Numbers (ERNs). However, this is not equivalent to ERNs but is the most primary word that can signify a certain condition independently in ICD–10.
Elements are categorized into nine groups:

- Disease condition: elements show condition, e.g., ulcer
- Morphology: for neoplasms
- Z-elements: elements contain ICD-codes themselves
- Modifier C: elements contain expressions ''gic,'' or ''phic,'' e.g., hemorrhagic
- Modifier D: elements indicate the stage of disease
- Sites: elements indicate parts of the body
- Common sites: e.g., stomach ''body''
- Y-elements: elements between modifiers and sites, e.g., ''upper''
- Special terms: ''due to,'' ''('', '')''

3) Element-code editing/check: Once medical terms are separated into elements, the broken up elements are combined to indicate CODs. The combined elements are called ''element codes,'' as shown in Figure 1.

Figure 1. Example of element codes

Right acute pneumonia

Elements: Y00004 D00297 A00493
Element code: Y00004 +D00297 +A00493

The process of elements codes modification/editing is as follows:

- Editing using special terms
- Interpretation of EC without condition terms
- COD contains more than two sites (reject more than three)
- Japanese-English
- Special treatment for neoplasms

The repeated element matching is performed until appropriate ICD–10 codes in the dictionary are assigned.

4) Coding: The ACSEL dictionary consists of element codes and ICD–10 codes. ICD codes are assigned after the matching process. The basis of this procedure is the ''exact-matching'' system. However, we often encounter different terminologies that can be summarized as synonyms. An example is ''heart failure.'' ''Chronic heart failure'' and ''acute heart failure'' can be categorized as ''heart failure;'' thus, there are no other optional modifications but heart failure for these medical terms. In the case of non-matching, repeated matching procedures are performed by the following methods, as illustrated in Figure 2:

- Remove modifiers except conditions and sites, e.g., ''right,'' ''acute.''
- If the site is clear, change the site to the wider/general range, e.g. ''foot'' to ''lower limbs.'' If it is not possible in this way, repeat the matching process with removal of every modifier except conditions/morphology or by recovering deleted modifiers.

Figure 2. Example of coding in the cause of non-matching

Malignant melanoma (MN) of right palm.

Right palm is non-matched to the dictionary. Change site: Rt palm? hand ? upper limbs and got the match. There is no difference between Rt palm MM and UL MM in ICD–10, thus assign the ICD code. The dictionary only carries MM of UL.

ICD–10 code modifications are made by age, sex, and duration of diseases, as illustrated in Figure 3.

Figure 3. Example of code modifications by duration

Brain hemorrhage: I619 (less than 1yr)
I681 (more than 1yr)

5) Rejected data: For those cases that can be processed but have coding problems, a ''warning'' error appears. When coding cannot proceed, a ''rejection'' message appears instead. For warned/rejected data:

- Change COD referring death forms, and re-enter Phase I
- Direct ICD-coding and put in Phase II (except neoplasms)
- Direct input UCD

Every step above can be performed at the PC level, which is extremely important because even non-perfectly-trained personnel can deal with the correction process that previously required special skills.

Phase II

In Phase II, ACSEL applies the WHO rules for selection of the underlying cause of death (UCD) in ICD–10 as ACME does. The major difference in this step between ICD–9 and ICD–10 is the selection method. We used pattern matching in ICD–9 system and found that the number of possible combinations was limited. The new system, the ''table method,'' accommodated the situation with the wide range of combination patterns that the new dictionary carried.

The first step is to determine a ''tentative'' underlying cause (TUC). Once TUC decided is, modification rules are applied to select an UCD. Since we have substantial numbers of reported ''heart failure'' because of culture (death aestheticism) and social indication, our own original rule is routinely applied in this process. We also carry out neoplasm automation coding in Phase II. The follows are principle concepts of Phase II:

- If only one code appears on the form, the code should be selected as TUC.
- If multiple codes, choose TUC from COD combinations according to the selection and modification rules.
- Phase C: decide TUC by Table C
- Phase N: neoplasms only
- Phase D: select UCD by Table D
- Phase E: change UCD if the chosen one is in Table E (trivial condition). If the trivial condition is the only listed one, issue warning.
- Phase S: apply Japanese rules (Table S)
- Phase F: remove reference characters (Table F)

Table C is the causal table, including the General Rule, Rule 1, and Rule 2; it consists of items that can be rephrased as ''B due to A,'' with the index code=B and the reference code=A. The principle of Table C is to choose index code B as TUC. In Figure 4, Example 1, malignant pleuritis is selected as TUC because of the established cause-effect relationship, but this cannot apply to Example 2 since there is no direct relationship between myocardial infarction and pneumonia; therefore, pneumonia is selected as TUC.

Figure 4. Example of selecting TUC.

Example 1
Malignant pleuritis C786
Stomach cancer C169

Example 2
Myocardial infarction I219
Pneumonia J189

Table D contains rules other than cause-effect relationships: Rules 3, A, C~F. Examples include LMP, where we select the reference code regardless of where it is, and LDC where we select the combined code if the index code is under the reference code.

Table E contains Rule B (trivial condition).

Table F addresses removal of reference characters to assign the official ICD–10 code. In this step, the reference marks, e.g., ''*'' and ''additional alphabets,'' are removed so that the assigned code is a reportable ICD code.

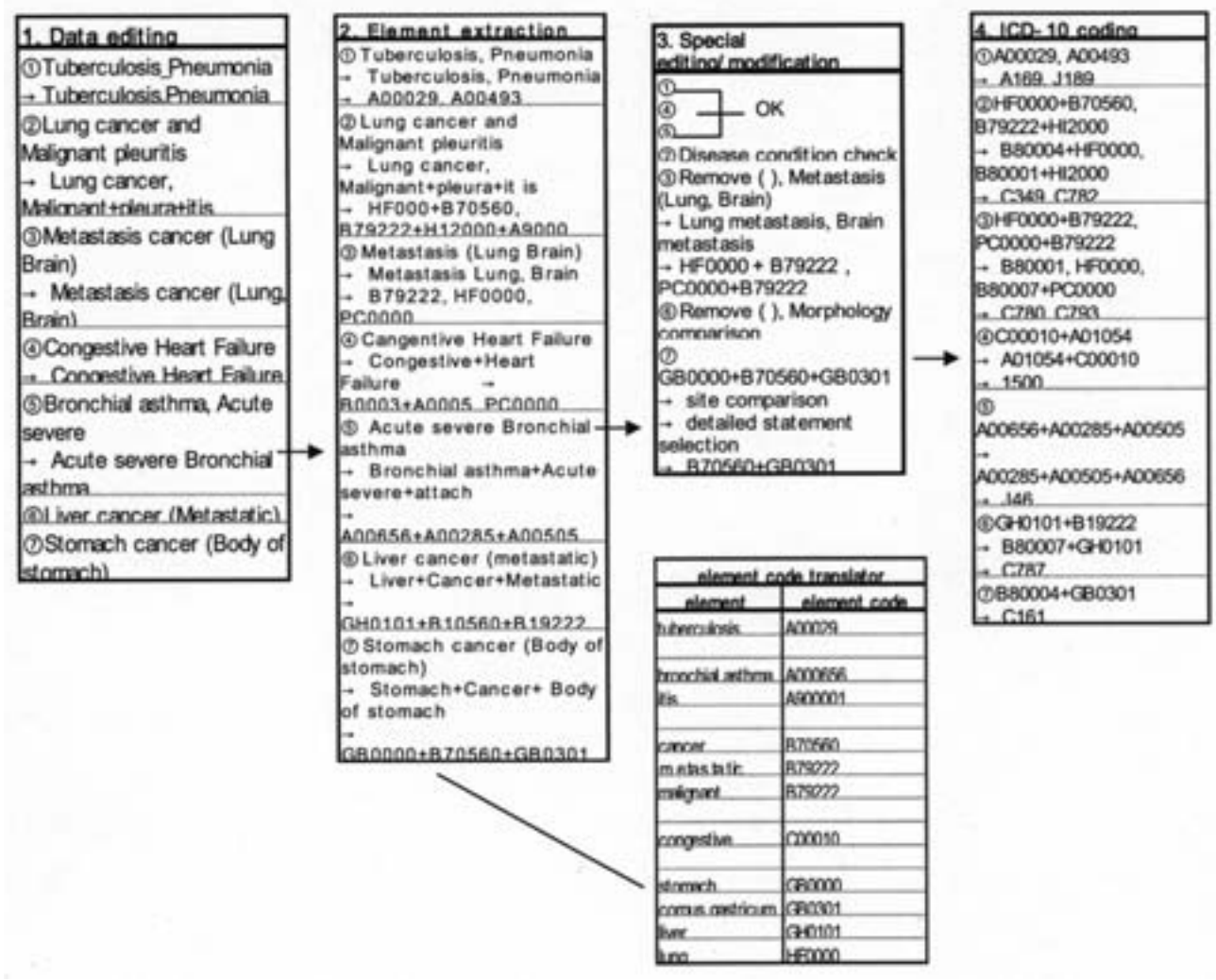
Table S contains Japanese rules. Since we have had a substantial number of ''heart failure'' deaths for various reasons other than the actual condition, ACSEL carries a special automated process to adjust the situation.

Issues

The development of the Japanese automation coding system took place in 1989. The new system, ACSEL, was implemented in 1995 without a delay in ICD–10 adoption and has been used up to now. It is based on the U.S. MICAR-ACME concepts, but the structure is unique to be compatible with the Japanese vital statistics system. There are two major improvements in automation coding from ICD–9 and ICD–10: (1) the assignment of ICD–10 code changed from the ''exact matching'' to the ''element combination'' method, and the dictionary differed in accordance with the transition (Phase I), and 2) the selection of UCD changed from ''pattern matching'' to the ''table'' method (Phase II).

With these developments, the overall agreement with manual coding improved from 71.4 to 95.4 percent. However, this figure can be improved by eliminating trivial errors such as misspelling, which usually happens when nonmedical personnel transfer the information from death certificates or medical charts to death register forms. To achieve the higher agreement, standardized training for nonmedical personnel as well as medical doctors needs to be aggressively expanded.

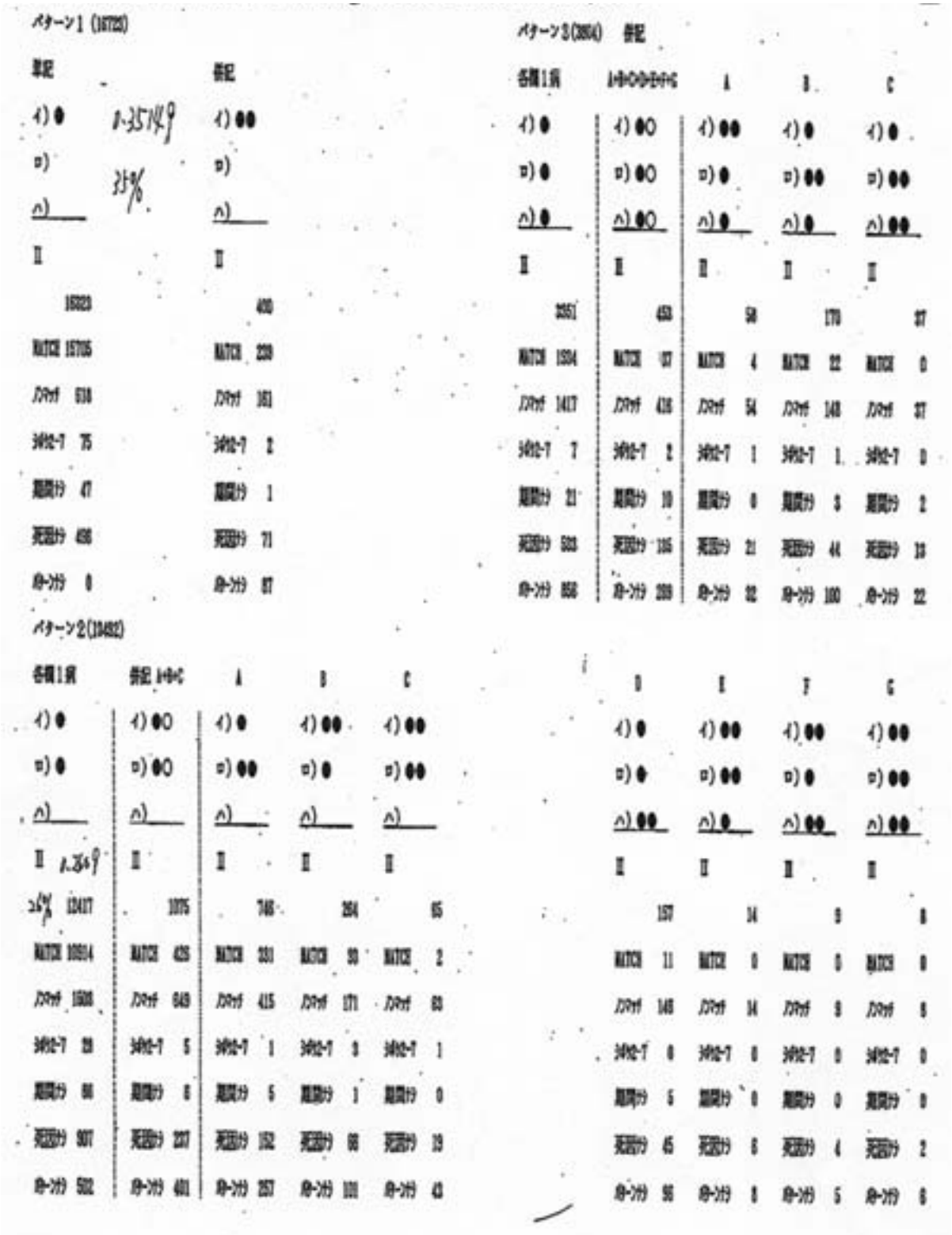
APPENDIX I. Phase I



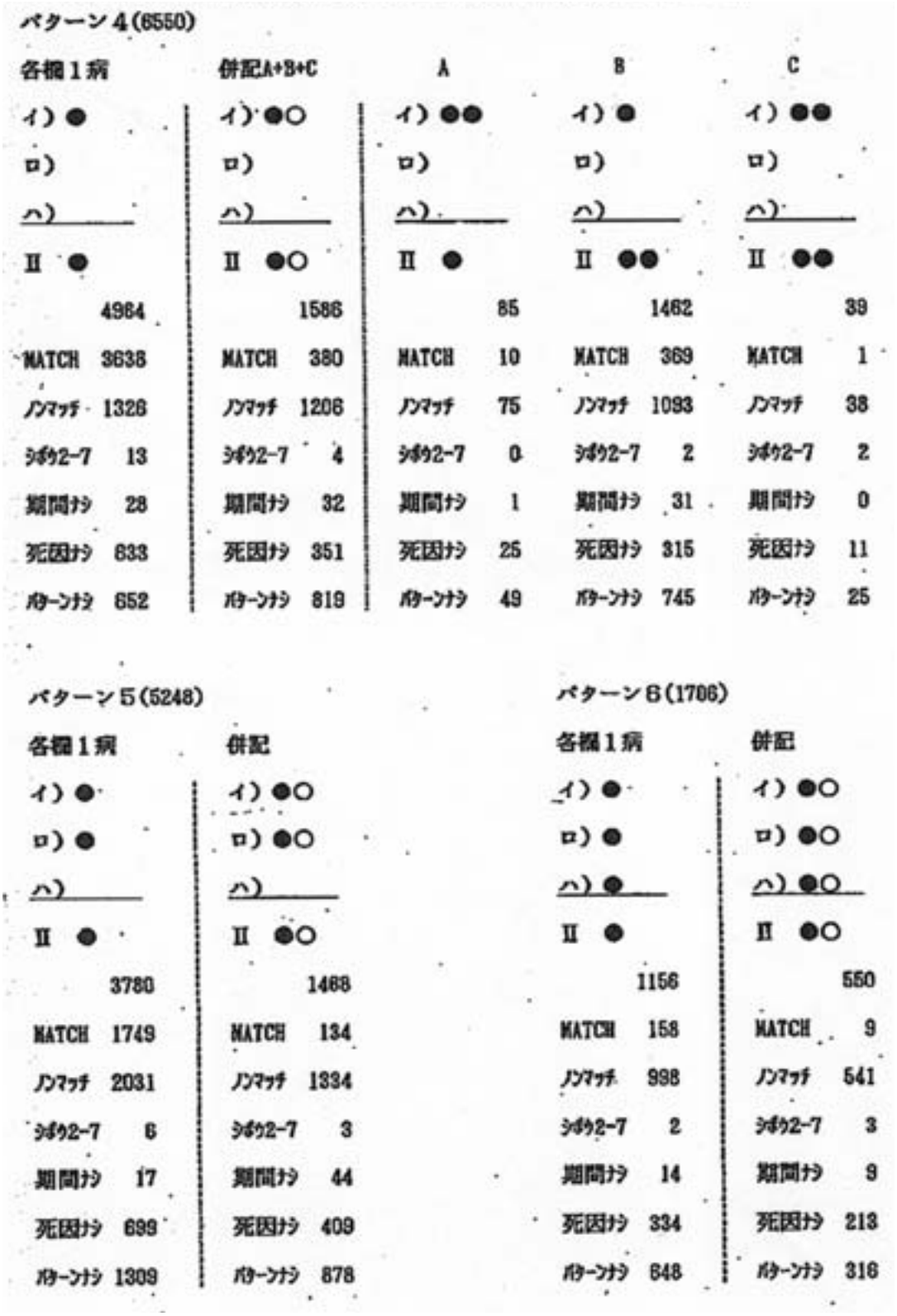
APPENDIX II. Acute Myocardial Infarction

APPENDIX III. Brain Haemorrhage (448)

APPENDIX IV. Pattern matching in ICD–9 automated system



APPENDIX IV. Pattern matching in the ICD–9 automating system (cont'd)



The Brazilian Diagnosis Coding System

Cassia Maria Buchalla, Ph.D., WHO Collaborating Center and School of Public Health, University of São Paulo, Brazil

The Mortality Information System

Brazil does not yet have a complete automating coding system, so this presentation is based on our current system that is improving. As it is changing, this is a good opportunity to discuss and learn from the experience of others. The mortality data system in Brazil is called Mortality Information System (SIM). Since 1976, the Brazilian Center has been working together with the Ministry of Health to organize and improve this system.

In the beginning, each State Health Department was responsible for its own mortality data. All death certificate information was coded at the State Health Departments and then taken to the Ministry of Health to be checked, corrected, and published. In the 1970s, we received ACME from the U.S. government, and it was installed in the State Health Department of the states of Sao Paulo and Rio Grande do Sul. This resulted in better data, as ACME automatically chooses the underlying cause of death. During the last decade, the Brazilian Health System has been changing; instead of centralizing all the health activities to the Ministry of Health, it has been decentralized. This means that all the health services, including data processing, began to be a municipality responsibility.

To avoid errors in the selection and coding of the underlying causes of death, the Brazilian Center planned to develop software for selecting the cause of death. This software is called ‘‘selection of cause of death’’ (SCB) and is based on the ACME Decision Tables.

The SCB software

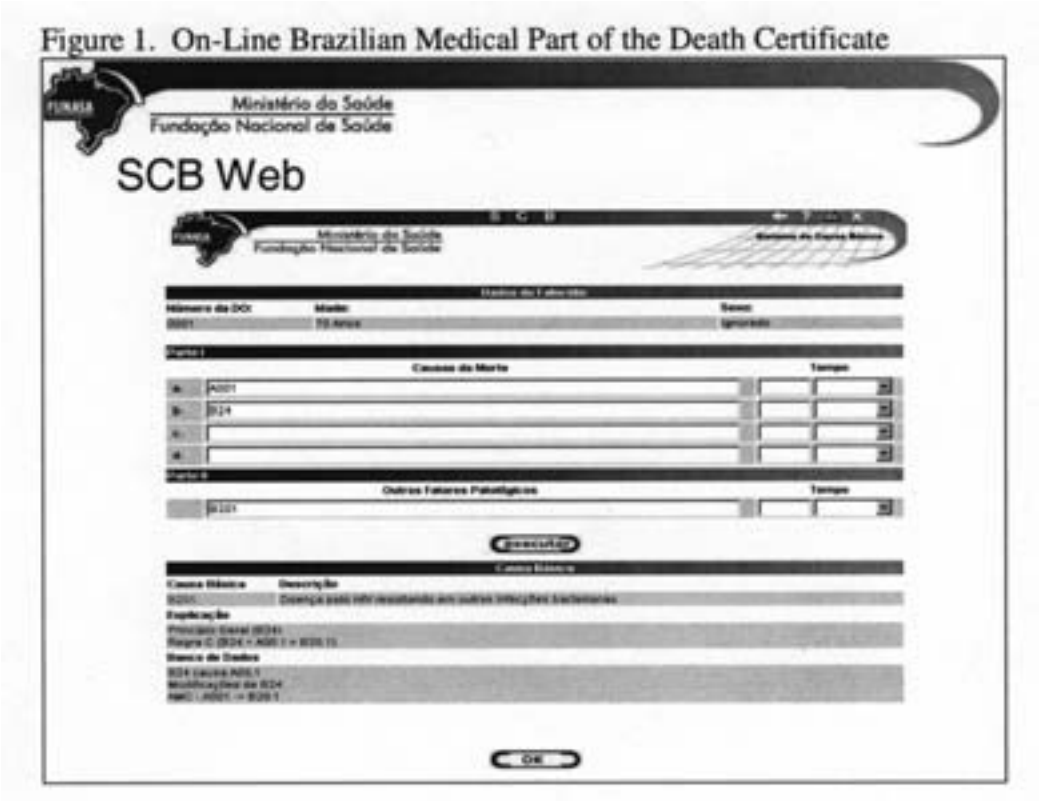
The first version of the SCB was created in 1993 for DOS using Turbo Prolog software. When the Tenth Revision of the ICD was adopted, a conversion table was created and new codes were included. Discrepancies were manually solved by the system analyst.

The SCB became a part of the Mortality System, which means that it was included in the software used by all Health Departments to provide the mortality database. Recently, the SCB was changed to an MS Windows platform. It is now developed in Delphi, which allows a DLL (dynamic link library) and an IIS (Internet Information Service) for a Web platform. It can be used online or offline. The last option could also be in a LAN.

It is a very friendly software program that dialogues with the coder during the process of inputting the data. After all the demographic information is typed into a screen that is a copy of the death certificates, the SCB selects the underlying cause of death from the medical codes.

The underlying cause of death is automatically selected but not automatically coded. After selecting the underlying cause, the SCB shows a box with the selection rules that are used to get the underlying cause and the sequences allowed by the ICD rules. Figure 1 shows the medical part of the death certificate.

Figure 1. On-Line Brazilian Medical Part of the Death Certificate



Coders enter the information such as sex, age, and all ICD–10 codes in the same way as the physicians complete the medical part of the death certificate. The bottom ‘‘executar’’ is pressed and the underlying cause is selected; the explanations appear on the bottom of the screen. When the ‘‘OK’’ button is pressed, the cause-of-death part is completed and sent, if online.

We have the option to use the software offline, which means that the Municipality Health Office will prepare a database to send to the Ministry of Health to consolidate all the country's mortality data. In this case, the software has small differences and the screen is shown in Figure 2:

Figure 2. Off-Line Brazilian Medical Part of the Death Certificate

All the inconsistencies and controversies are discussed by a group of experts on mortality. The Brazilian Center plays an important role in coordinating meetings and workshops to improve coding and to support the mortality coders' network.

How the software works

This SCB software works with 12 Decision Tables. One of them is the ''master'' that holds all ICD codes. The others are tables that explain modifications needed to decide the real cause of death. One table has all modifications; another has all the trivial codes; another lists all the ill-defined conditions, and so on. There is also a group of exclusion tables. All tables are listed in Figures 3 and 4 below:

Figure 3. Tables in the SCB System

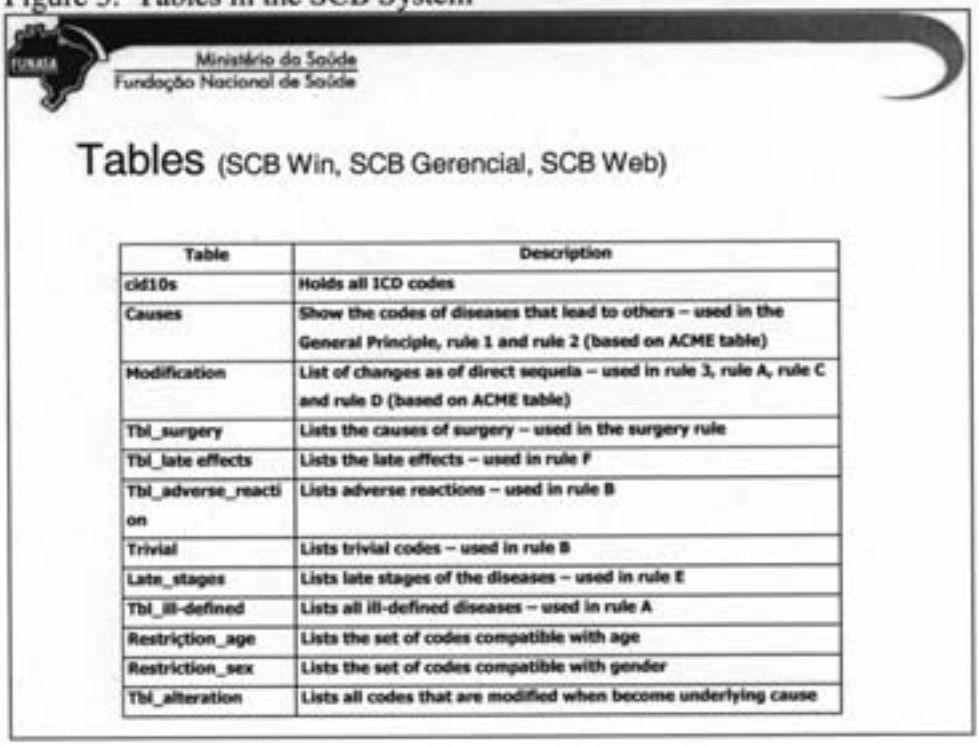
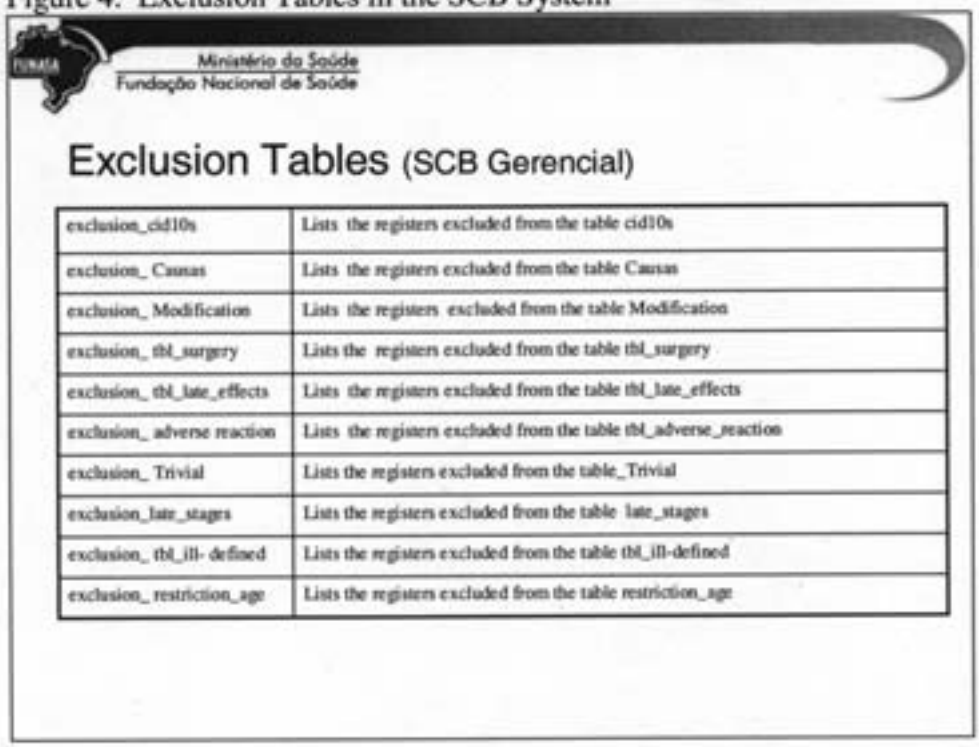


Table	Description
cid10s	Holds all ICD codes
Causes	Show the codes of diseases that lead to others – used in the General Principle, rule 1 and rule 2 (based on ACME table)
Modification	List of changes as of direct sequela – used in rule 3, rule A, rule C and rule D (based on ACME table)
Tbl_surgery	Lists the causes of surgery – used in the surgery rule
Tbl_late effects	Lists the late effects – used in rule F
Tbl_adverse_reacti on	Lists adverse reactions – used in rule B
Trivial	Lists trivial codes – used in rule B
Late_stages	Lists late stages of the diseases – used in rule E
Tbl_ill-defined	Lists all ill-defined diseases – used in rule A
Restriction_age	Lists the set of codes compatible with age
Restriction_sex	Lists the set of codes compatible with gender
Tbl_alteration	Lists all codes that are modified when become underlying cause

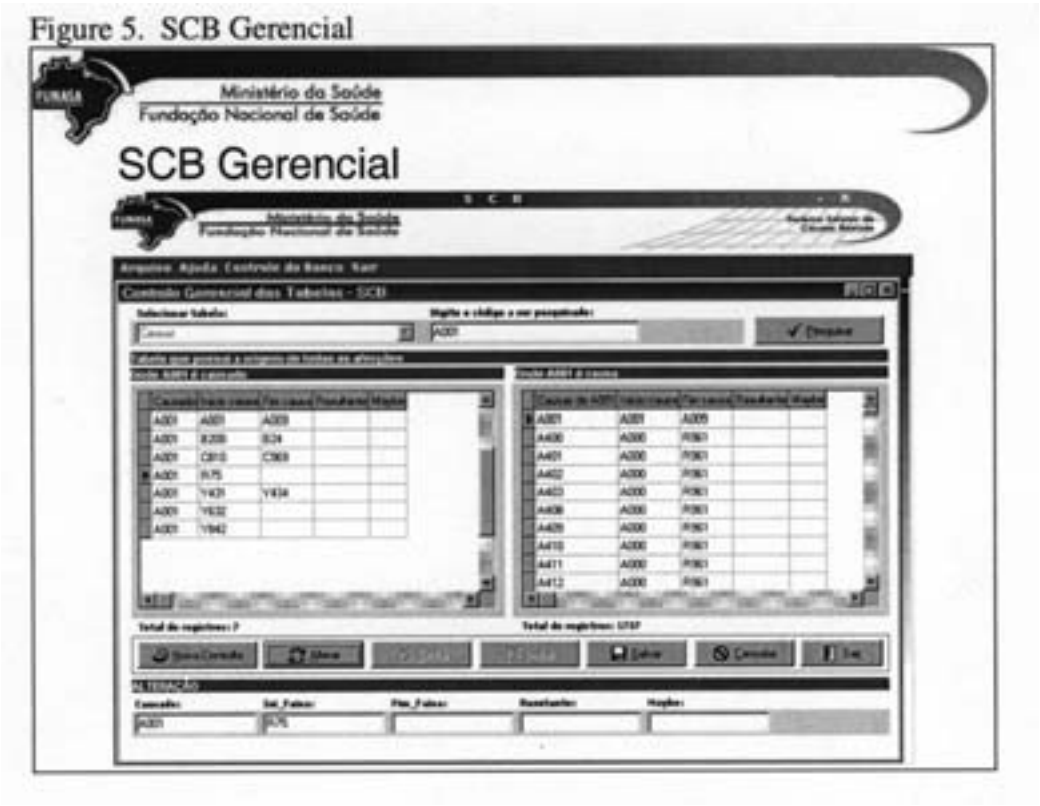
Figure 4. Exclusion Tables in the SCB System



exclusion_cid10s	Lists the registers excluded from the table cid10s
exclusion_ Causas	Lists the registers excluded from the table Causas
exclusion_ Modification	Lists the registers excluded from the table Modification
exclusion_ tbl_surgery	Lists the registers excluded from the table tbl_surgery
exclusion_ tbl_late_effects	Lists the registers excluded from the table tbl_late_effects
exclusion_ adverse reaction	Lists the registers excluded from the table tbl_adverse_reaction
exclusion_ Trivial	Lists the registers excluded from the table_Trivial
exclusion_late_stages	Lists the registers excluded from the table late_stages
exclusion_ tbl_ill- defined	Lists the registers excluded from the table tbl_ill-defined
exclusion_ restriction_age	Lists the registers excluded from the table restriction_age

The software can be easily modified using an internal component called ''SCB Gerencial.'' Thus, it is possible to introduce a new sequence, a new selection rule, or a new code. While SCB Gerencial is very friendly, only a few people have access to it. The screen is shown in Figure 5:

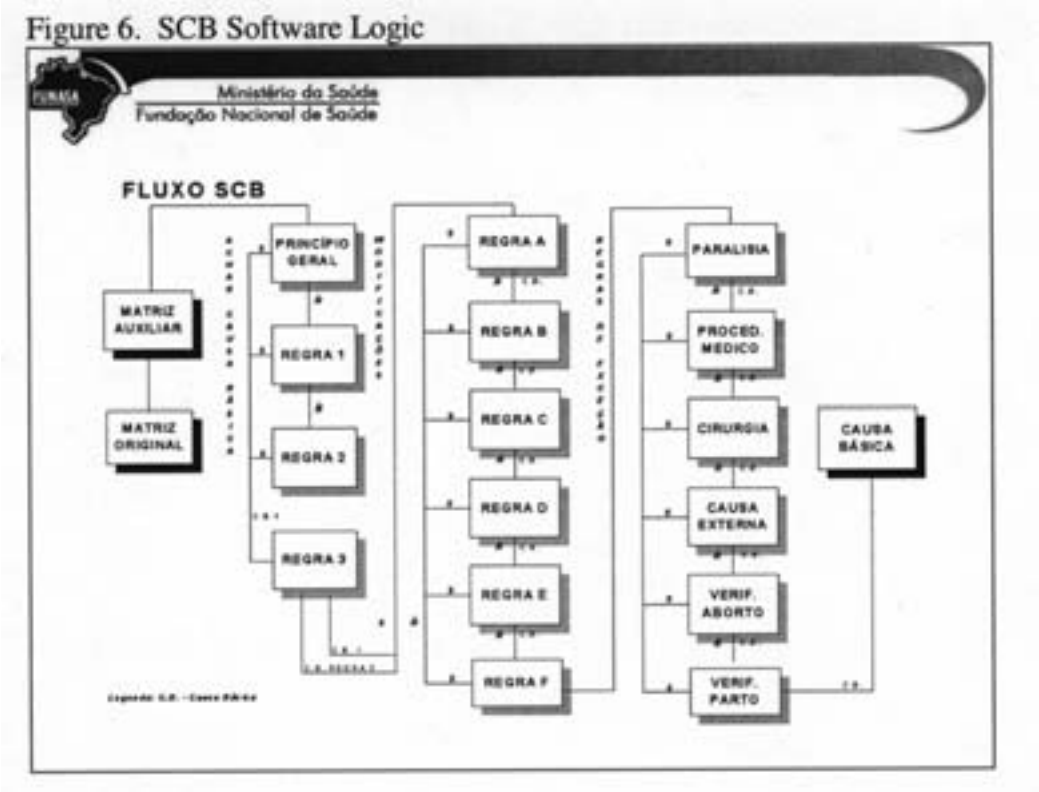
Figure 5. SCB Gerencial



The SCB software works through making a sequence of matrices. When the user types a sequence of codes, as reported on the death certificate, the software makes an ''original'' matrix. Then the software mimics our judgment ands start to check if these causes are related to each other or not. The process continues, applying all the selection rules for the underlying cause of death.

Figure 6 shows how the software determines underlying cause of death. Each box is a coding rule, namely, the general principle, the rules (1, 2, 3, A, B, C, etc.,); the letters are S = yes; Ñ = no; and C.B. = underlying cause of death.

Figure 6. SCB Software Logic



Of course, this is just a summary of a more detailed process. The software also considers the number of lines that were completed, how many codes are in each line, and where the underlying cause of death was reported. This software represents a very important step to better quality of the mortality data. To have this working online is our goal for the next semester. Another important goal regarding the SCB is to build a dictionary that can be used for multiple-cause-of-death analyses.

Discussion on Presentations of Session 4

S. WALKER: Sue Walker from Australia. It seems to me that my current SuperMICAR should be able to have a broader application than just coding for mortality. Does anybody have any experience in using the same sort of logic for coding morbidity, particularly for electronic records?

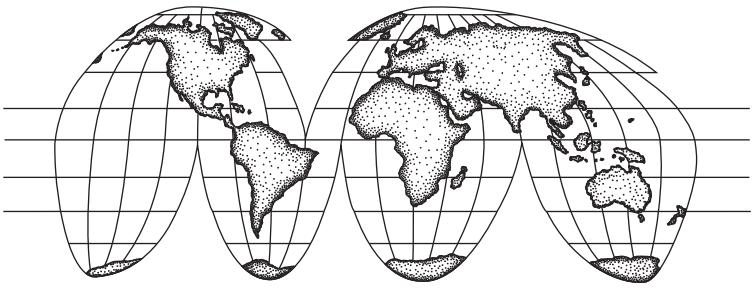
D. GLENN: I have not done it but know of some interest in this. I think that anybody who codes should be able to use the same type structure to code other things. We also have a dictionary. . ..

M. KIMURA: I think in our country, we do not have the same dictionary, but we have a dictionary for morbidity. I do not know if exactly the same process can apply.

L.A. JOHANSSON: I could see a few difficulties with using the MICAR system for morbidity since it requires statements of ''due to'' relationships that you generally do not have in hospital records. Otherwise, there should not be any problems.

SESSION 5

Electronic Files



Session 5: Electronic Files

Dr. Michael Schopen (moderator), German Institute of Medical Documentation and Information (DIMIDI), Germany

I shall give a brief introduction to the program of this session because you may be quite uncertain whether you are in a session on mortality or in a session on morbidity. I think morbidity can learn from mortality, and mortality can learn from morbidity. Due to the new updating mechanism for ICD–10, mortality is facing problems that morbidity has been facing for many years. Morbidity classifications are much more dynamic than mortality classifications; morbidity people want to cover current medical knowledge. On the other hand, mortality people want to keep their statistical data consistent over a long time and are quite resistant to changes in the classifications.

The question today in this session is what can you learn from the morbidity people? How do they maintain their classifications? How do they keep track of the versions? In their presentations, both Sue Walker of Australia and David Berglund of the U.S. take the database approach. I presented the mark-up language approach during the last ICE in 1999; today, Karen Horne of Canada is presenting a hybrid approach: taking a mark-up language, XML, and storing it in a relational database.

In addition, I will give a presentation about the dictionary index problem and, finally, Christiane Rosenow from the German Federal Statistical Office is going to show how mortality data can be presented on the Internet.

I shall start the session by giving a brief overview of the Electronic Tools Committee of the WHO Collaborating Centers for the Family of International Health Classifications.

The Electronic Tools Committee of the WHO Collaborating Centers for the International Family of Classifications

Dr. Michael Schopen, German Institute for Medical Documentation and Information (DIMIDI), Germany

The Electronic Tools Committee was founded in 1999 at the Cardiff Annual Meeting of the WHO Collaborating Centers. Its scope is to advise WHO and the Collaborating Centers on policies towards electronic tools related to their classifications. It is quite easy to become a member of the Electronic Tools Committee, as it is open to any individual from collaborating organizations who wish to participate in the work, and we should stress the word ''actively.'' There is a lot to be done and we need people who do the work. To become a member, simply submit your name to me, the chair, and supply WHO with a copy of the submission.

What do we do? First, we agreed on the scope and the definition of ''electronic tools,'' and we agreed that we should cover both morbidity and mortality tools, as well as tools with a more general approach. Since all WHO Collaborating Centers will become collaborating centers for both the ICD and the ICF (The International Classification of Functioning, Disability and Health), the Electronic Tools Committee will cover ICF-related tools in the future. We work closely with other groups and other people working in related areas, and one of these areas is the ICE, which is why I am here. We have to establish criteria for the evaluation and accreditation of electronic tools and, in some circumstances, even evaluate tools on behalf of the WHO. One of our tasks was to survey existing tools and to identify gaps and pressing needs for the future.

What have we achieved so far? We have established a communication platform, which is presently e-mail communication. We are about to set up a Web-based discussion forum, but it will take some time to work without technical problems. We have also established personal links to people working in related areas, and we have to advise WHO on a dissemination policy for ICD–10. As many of you know, ICD–10 is not available on electronic media from WHO at the moment, and we have advised how to overcome the situation. In addition, we have surveyed the Collaborating Centers and related institutions on ICD-related electronic tools. We have the results of this survey available; we also have information about our ICD-related electronic tools such as relevant contact persons, tool features, availability and licensing information, and so on.

Work in progress includes an electronic version of ICD–10, which should be available in early May or mid-May. It will be based on the extended mark-up language. It will contain a browser, which makes use of the portable-document format, so you can use it with the Acrobat Reader. It will be available as a read-only version on the Internet without any charges. For software companies, a bundle of files in different formats will also be available on a CD-ROM, which will require a license from WHO for commercial use.

Another project for which the Australian Collaborating Center has taken leadership is the ICD–10–XM. As many of you know, we have an AM, an Australian Modification. We have a CM, a Clinical Modification in the U.S. Canada has a CA, a Canadian Adaptation. We have a GM in Germany. Now, why should we not have an XM, an Extended Modification? We will start with a morbidity meta-database, which contains all existing clinical modifications. With this meta-database it should be possible to realize where existing clinical modifications could be harmonized. This meta-database could also be a place where countries that need a known clinical modification can go to pick up certain diagnoses and see how to subdivide them on the fifth- or sixth-character level. We hope that this meta-database, after harmonization, may lead to an international clinical modification. While I am a bit skeptical about that, because clinical modifications are always somehow tied to the reimbursement systems of the countries, I still think it is a perspective to follow.

ICD–10–AM in a Database

Sue Walker, National Center for Classification in Health, Brisbane, Australia

The NCCH database that I am going to describe was developed in the Sydney office; we do not actually use it in Brisbane. This presentation will describe the development of our database, which we have now had in operation for several years now. This is the database used to develop and maintain the Australian classification, the ICD–10–AM. The paper will describe the background to the development project, the aims of the development, the business rules that we developed to guide the use of the classification and the database, the development phases, and then some lessons we learned that may be applicable if we decide to develop an ICD–10 database.

The ICD–10-AM is currently published as a five-volume book set. The five volumes consist of Volumes 1 and 2, which are the Index and the Tabular List of Diseases based on the WHO's ICD–10. Volumes 3 and 4 are our Procedure Classification Index and Tabular List, based on the Australian fee schedule used by physicians. Volume 5 is what we call the ''Australian Coding Standards,'' which are basically coding guidelines to assist coders to make standardized coding decisions.

We implemented the third edition of the ICD–10-AM on the first of July last year, and we plan to implement the fourth edition on the first of July next year. We are currently in the final stages of development of the fourth edition.

We decided to develop a database version because we thought that there were limitations in having only a hard copy of the ICD–10 available. We called for expressions of interest, reviewed bids, and awarded the work to a software company known as Central Software, a Sydney-based software development company. The contract was awarded in late October 1998. The aims of the software-development project were as follows: first, to streamline in-house maintenance of the classification, which is a core function for the National Center for Classification in Health. We initially produced the classification in January 1998. To update, we used the Microsoft Word ''find'' or ''search and replace'' functions. We then imported the files into Word Perfect to spell check them because, at that time, the English and Australian medical spell check was available only in Word Perfect. We then exported to Quark Express to produce the publication. Because of the number of steps in the process, we felt the need to streamline those processes.

The second aim was to provide us with a tool for further development of the classification. For example, we are right in the middle of developing an Australian clinical vocabulary, which is based on our Index. We thought that the database would provide us with useful assistance in that development.

We also wanted to be able to create links within ICD–10–AM, such as links to instruction manuals and coding standards, and link things that are in the Index with their entry in the Tabular List. We wanted to be able to develop data export formats to be used both by the NCCH and software developers, and we wanted to be able to produce subsets of the classification and products to assist coders, such as browsers.

Finally, we wanted to provide an interface for desktop publishing. Prior to commencement of the development of the database, the NCCH staff developed business rules, and examples of some of these are the use of abbreviations. For example, NEC, we specified stands for ''not elsewhere classified.'' While that is quite obvious to us, it is quite incomprehensible to the rest of the world, so we specified that NEC can only appear as an abbreviation in the Index. Secondly, we specified what annotations are being used, for example, ''em dash,'' daggers, and asterisks. ''Em dash'' are those hyphens that you see in the Index indicating the different levels of modification; dagger and asterisk are etiology and manifestation codes. The rules for prepositions, ''as,'' ''by,'' ''for,'' ''with'' and ''without,'' take precedence in the Index, and, therefore, we needed to specify that they are an exception to the alphabetic rule that you normally see in the Index. We specified that nonessential modifiers must always be in alphabetical order. Inclusion terms are located in the Tabular List directly under the code and the code description and before any other notes; for example, inclusions and exclusions. We indicated that instructional notes such as ''includes,'' ''excludes,'' ''see,'' and ''see also'' are always found after the inclusion terms and before the exclusion notes.

We also developed rules for tables. As you know, there are four tables in ICD–10; therefore, there are four tables in ICD–10-AM, and we provided rules for developing the latter. To give you an example of how

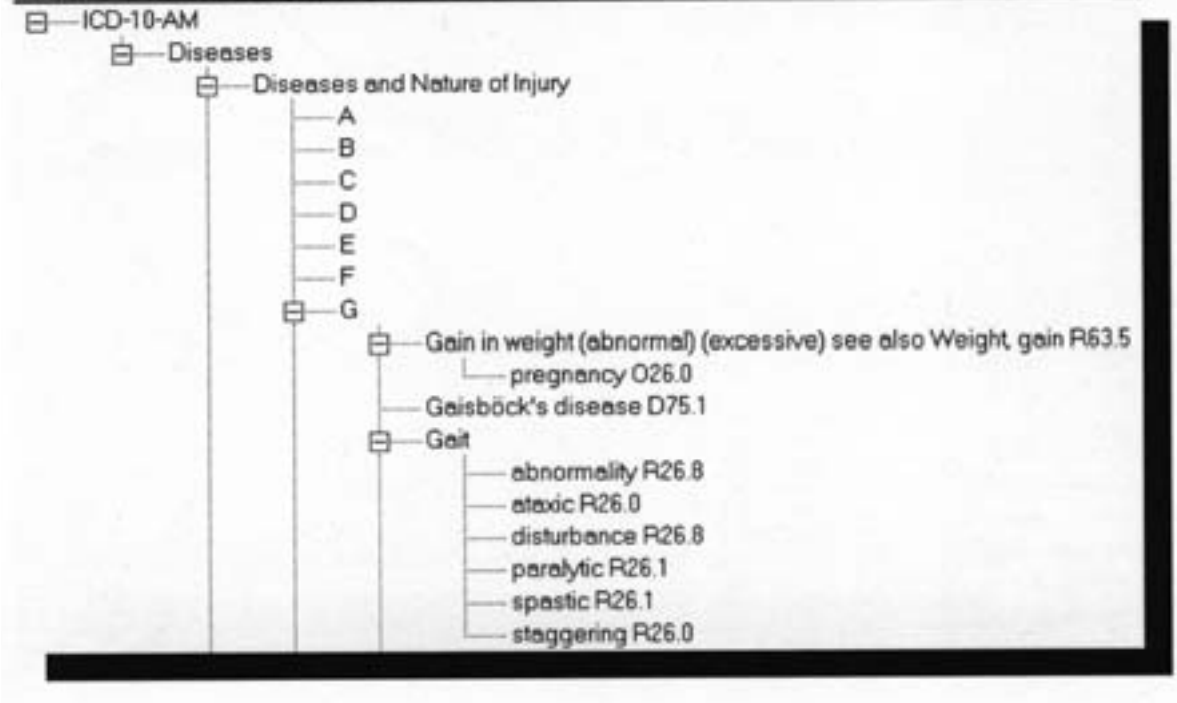
these rules affect the Classification, the nonessential modifiers are in alphabetical order. For example, under ''deaf mutism'' we have ''acquired'' and ''congenital'' in alphabetical order, followed at the end of the code description by NEC. So that comes after the nonessential modifiers and before the code. Daggers and asterisks are sequenced with the etiology first, the manifestation second, and, in this example, the preposition ''with'' comes before all the alphabetic listings. The four tables are dynamically loaded. These are the tables for abortion, neoplasms, land-transport accidents, and drugs and chemicals. We can actually add new tables as the need arises. We can actually click on the code reference and view all the Tabular List entries for that particular code.

Following the development of the business rules, we commenced programming in late October 1998 and completed it about 10 months later. The project consisted of five phases, which were as follows: 1) the definition of the database specification and design, 2) conversion of our existing word files, 3) implementation of our initial required functionality, which included edit, search and report, 4) implementation of export scripts and our interface, and 5) delivery of the product to NCCH and acceptance testing.

During the first phase, we made the decision to use Microsoft Access as database product because we all used the Microsoft Office Suite, so Microsoft Access was readily available to us. Access can be easily converted to SQL in the future, if the need arises, and we anticipated that most potential customers would be familiar with Microsoft Access. We did have a few concerns including whether the database would be robust enough to handle the size of the database, whether the multi-user access would work properly, and whether it would be fast enough. In fact, we found that these are not major issues in practice. We decided on a tree structure to explain how both the Index and the Tabular List look because of the hierarchical nature of the Classification. This design also allows us to specify relationships between the components of the Classification.

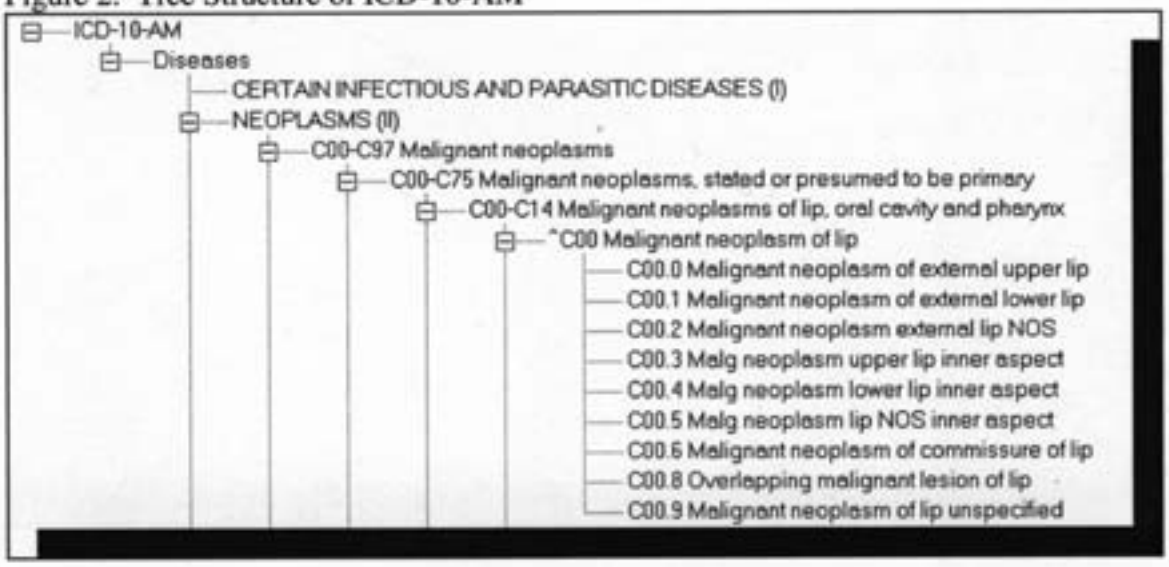
In Figure 1, you can see the levels of specificity from the Volume of the Classification to the chapter level to the code level.

Figure 1. Index design of ICD-10-AM



In Figure 2, we show the Tabular tree structure that we developed from the Volume through to the chapter to the section, the category, the block, and finally the code. We found some inconsistencies in the chapter structures between each chapter. Figure 2, which is the design for the neoplasms chapter, has one more level in the tree than some of the other chapters.

Figure 2. Tree Structure of ICD-10-AM

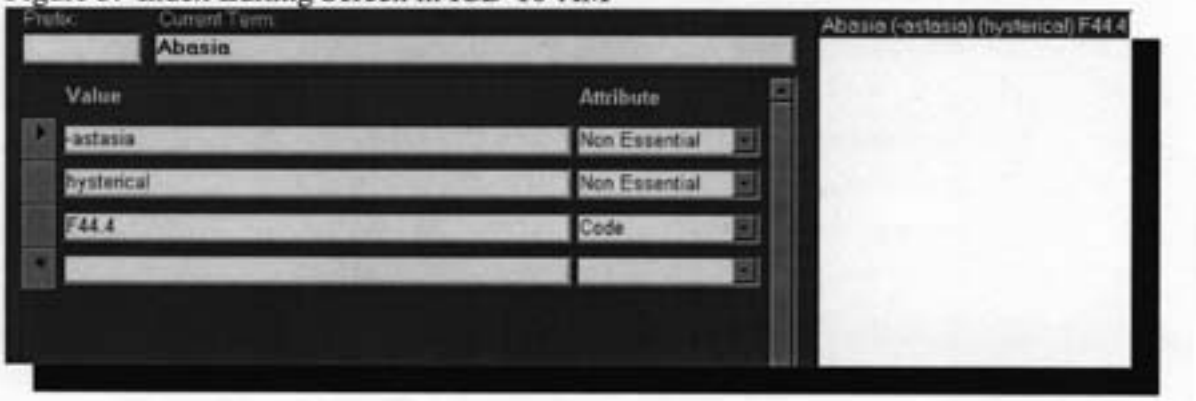


Our next phase, which was to convert our existing Word files, was actually the most time-consuming part of the whole project. To facilitate this, our NCCH staff actually undertook the task of applying styles to each component and then amending the files to allow the developers to distinguish between those different components in the Classification. For example, we had a different style for chapter headings, for block headings, for categories, for codes, for includes and excludes, notes, etc.

The third phase was the implementation of the edit, search, and report functions. For example, at the main tree view, clicking on ''Detail'' allows us to add edits, additions and deletions at the next level of the classification. Figure 3 shows the sort of screen you get, in which you can click on the detail. You get an Index-editing window, which permits editing of the attributes of each particular entry. In this case, our lead term of ''Abasia'' has two non-essential modifiers, ''-astasia'' and ''hysterical,'' and the code of F44.4.

To assign the attributes, we have a drop-down list that includes things like ''code,'' ''code also,'' ''code as,'' ''code by,'' ''code to,'' ''dagger,'' ''diamond,'' ''hash,'' ''morphology''—all the usual conventions in the ICD. Each attribute is assigned a sequence number to ensure that it appears in the correct position within the tree.

Figure 3. Index Editing Screen in ICD-10-AM



In the same editing window, we can also do some smart things like asking to see all occurrences of a particular attribute in a particular volume. For example, we have a little button that says, ''Index Reference,'' which allows us to look for all occasions in the Index where the code is specified as F44.4. We can also use that not only for code references, but for references for any other attribute, for example, all the index entries that include the word ''hysterical'' as part of the code title. We can also do this with the Tabular list, with the Coding Standards, and with the Procedure Volumes.

The fourth phase was development of export scripts and the interface with our desktop-publishing software, which allows us to export directly into Microsoft Word. We can export the whole Classification or subsets. The subsets can be based on code number or by word ranges within the Index. For example, starting at the word ''coma,'' we can export everything to the end of ''comminuted fracture.'' We use style sheets to ensure that when the data gets into Microsoft Word, it looks like ICD–10. We then flow into Quad Express for Desktop Publishing. Unfortunately, human intervention still has to occur at this point because we need to proofread to make sure there are no spelling mistakes in the Classification. This is a huge job.

This whole project was completed in August 1999, and we have been using the Classifications since then in the database format. We have also developed several other products to support our coders, including a browser of ICD–10–AM on CD-ROM. Also, we have an e-book that allows coders to make their own notes against each code. We have also developed subsets of the Classification for use in special areas, such as early parenting centers and mental health centers.

What is our future direction? We believe that we have gained a lot of knowledge from this project that will assist WHO in its vision to have a standardized electronic format for ICD–10. We are developing an Australian clinical vocabulary or terminology based on the Index, but adding terms that are used by Australian clinicians to describe the diagnoses and procedures that they see. Finally, Australia is right in the middle of developing processes for electronic health records, for which our database will serve as just a small part of the whole jigsaw puzzle.

Thank you.

The Development of a Database Version of ICD–10–CM

Dr. David Berglund, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

In this overview, I am going to talk about our goal concerning development of a database version of ICD–10–CM. We want to have a machine-readable format that will provide benefits to our users, such as data exchange. We want to support open formats with this. I am also going to review our ICD–10–CM development and then provide more details about our database development for ICD–10–CM and related issues.

First, some of our considerations: why a database? Users requested a machine-readable format because they wanted to be able to load it into their own database systems. Among the options we considered for maintenance were the Folio-InfoBase Format, Standard Generalized Markup Language (SGML), or a Relational Database Management System.

We are using right now the Folio-InfoBase Format for maintaining ICD–9–CM; it has a number of benefits, including handling long text fields, quick searches, efficient hyperlinks between files, and familiarity to our users (it has been in use for maintaining ICD–9–CM since 1994). However, there are also some drawbacks, including a proprietary format; it requires Windows for the viewer, and there are royalties per copy on that. In addition, yearly updates are somewhat tedious, and tracking takes a double effort. Another big drawback is that it really cannot be easily exported to a format that can then be imported into a database.

We considered SGML, with which an excellent form of ICD–10 was created by Michael [Schopen of Germany] and others. However, we would have needed some structural additions to handle ICD–10–CM. Also, sophisticated SGML editors have been expensive. Various options include Word Perfect, which has some SGML capabilities that are rather rudimentary and did not support some of the things that would have been needed; a high end for this was not really in our budget for experimentation. Also, our users want a format they can load into database systems. While tagged formats like SGML can be used with transforms, it appeared to be easiest just to directly use a database system for maintenance.

Consequently, we are going to maintain ICD–10–CM in a relational database management system, specifically Microsoft SQL Server, and our development is now using Visual Basic.NET. We used earlier versions of Visual Basic, to which I will return.

What are the benefits of maintaining ICD–10–CM in a database, and what are our needs from it? The goals are to allow output to multiple distribution formats, to support yearly updates more easily than the Folio version that we are now using for ICD–9–CM, to have something users can easily load into their own database systems, to support creation of mappings from other terminologies, and to enable development of systems for data exchange that will benefit people who are transitioning from ICD–9–CM to ICD–10–CM.

Why was a Clinical Modification needed, and what was its purpose? Basically, we needed to expand distinctions for ambulatory and managed care encounters. We also wanted to expand and include new concepts for emerging diseases and more recent medical knowledge, and we wanted to incorporate changes that we had made to ICD–9–CM, since ICD–10's implementation. Development of ICD–10–CM followed three phases: 1) a prototype was developed with a technical advisory panel; 2) enhancements were made by NCHS using our coordination and maintenance minutes for ICD–9–CM, with input from providers and other users; and 3) further enhancements were made based on public comments. We did consult with a number of physician groups, professional organizations, and other users of ICD–9–CM.

In the ICD–10–CM development, major modifications were made, including addition of a sixth character, and, in certain places, seventh-character extensions. Added details include laterality, trimesters for obstetrics, new expanded codes, for example, in the injury section, and revised codes in the diabetes section. We have also combined certain codes, including the dagger and the asterisks codes as in ICD–9–CM, combined certain diagnosis and symptom codes, and deactivated procedure codes that were in the Classification in anticipation that these would be captured using a Procedure Classification.

What are some of the advantages that we will have when we move to ICD–10–CM? This will let us update the clinical language used; will let us capture data on factors other than disease affecting health; give

us comparability with the state and the national mortality data; improve data for epidemiology and decision-support reasons for things like patient safety, outcomes research, ambulatory and managed care encounters, surveillance and prevention activities, and refining applications like grouping and reimbursement methodologies; and will let us harmonize with other classifications, such as DSM–IV–TR and ICD–O–2 and nursing classifications, among others.

As to the recent status of ICD–10–CM, we have completed our incorporation of public comments; finalized the Tabular List revisions and revisions to the Index and crosswalks; and revised the Guidelines. We did get to an Alpha version of the database. We also need to develop training materials, and we will have a pre-release test and a Comparability Study. Following that test, we may have additional changes to some of the other components that otherwise might be essentially completed.

I will talk now about some of our requirements for database development for ICD–10–CM: we wanted support for data conversion; searching and browsing capabilities; editing; maintenance; and the ability to output to other formats.

The data files have been created in a word-processor format. They have now been moved into a Folio Info-Base Format that can output to a word-processor format. Data conversion then will need to go from a word-processor format into the database, initially to load the database, and during that conversion process to have data integrity checks to ensure that there are no errors or problems.

There are other requirements: with respect to searching and browsing, we need to support sophisticated queries. We need to be able to browse using hyperlinks similar to what Web pages use; Folio, of course, has supported this for ICD–9–CM. We also want to easily be able to switch between different files, such as the Index and the Tabular List within one application.

For editing and maintenance of ICD–10–CM using the database, there are a number of things we want, including easily restricting editing to certain individuals. We also want to be able to track and report changes made during the maintenance process, and finally, we want to be able to allow external systems to be easily updated.

In terms of output to other formats from an ICD–10–CM database, we plan for multiple formats, including plain text, which can be loaded into other database systems. We want to have mark-up language, such as HTML, XML and SGML for both support on the Web and also potentially for publishing purposes. We want to support PDF (portable document format) that is also widely used on the Web. We also want to be able to supply word-processing formats, and we do want to be able to supply a Folio Info-Base product for interested users.

The database environment for ICD–10–CM will be Microsoft SQL Server. As indicated earlier, we did initial work using Word for editing via a Visual Basic program, a sophisticated approach, but it was prone to problems. We subsequently changed our approach to Visual Basic.NET for development and doing essentially a stand-alone application. We will initially have a less complex implementation of it but plan for future enhancement. In some respects, ''the perfect could be the enemy of the good.'' We do not want to try to hold off on having something that is useable until it is perfect. We need more immediate functionality and something that will work, even if it is initially a little bit more basic. We did end up setting aside some of our earlier work as we moved to an updated system. We are still working on development of the system.

Briefly, some of the implementation issues that will be faced are as follows: training will be required for users at various levels. Coders should not need extensive retraining, since the structure, conventions, and coding rules are basically the same as for ICD–9–CM, although there is expected to be some short-term loss of productivity. It will require changes to data systems. It will also enable improvements in data retrieval and analysis, and it will support creation of mappings from other terminologies or vocabularies. It will also help enable development of systems for data exchange for more easily supporting electronic data exchange.

Further work will be required to get us to the point where we are ready for the move to ICD–10–CM. Based on some of the political process that will need to take place for this, we anticipate that the earliest ICD–10–CM could actually be implemented will probably be 2006.

There is certainly going to be a lot of interest in electronic tools to support the move from ICD–9–CM to ICD–10–CM, including interest in automated morbidity coding. While a lot of people have an interest in this,

it is not as far along as automated mortality coding from which we in morbidity have something to learn. I will close by noting our Web site for the NCHS Classification, which has information on ICD–9–CM and ICD–10–CM, as well as a draft of ICD–10–CM in PDF format.

Thank you.

ICD–10–CA the XML Way: The Canadian Approach to ICD Electronic Publishing

Karen Horne, Canadian Institute for Health Information, Canada

We Canadians have taken a hybrid approach. We have used XML in order to make the transition from the relational database to electronic publication as smooth as possible. This has been a team approach, including partnerships among the Classifications Department, the IT Department, and some consulting companies.

We recognized that we did not have a lot of expertise in electronic publishing. We are a company that collects and analyzes data, but we had never published a classification system before 2001. Consequently, we brought in a company called Newbook Publications, whose expertise was in publishing. They also used open-source solutions to meet complex information needs, which was certainly what we had in the ICD.

The internal staff members at CHI have been working with the consultants for 4 years to build the system that we have today. The consultant also played a key role in our recent data architectural review. I am going to spend more time describing the revisions rather than how we loaded the original database back in 1999.

Our Newbook consultants recommended that we add XML to our database as well as make other major enhancements to the database model itself. Another company, with which we formed a partnership, is called Alpnet (in Montreal). Alpnet, which specializes in translation, helped us create our first publication in French as of April 1, 2003; this has been distributed to our clients in New Brunswick for use in this coming fiscal year.

I will present a little bit of history of Version 1, the relational database model whose development started in 1999. Code descriptions, validations, and conversions were loaded from the Microsoft Access database that we had developed; a considerable amount of processing was required to convert. We took the WHO Word Perfect files and converted them to ASCII text, which was used to load the inclusions, exclusions, notes and the Index into our sequel-server version of the database. In April 2001, we published our first version of the ICD–10–CA on a Folio CD-ROM, as well as five printed volumes that were sent to the implementing provinces.

In Canada, we have had a staggered implementation. In the first year, 2001, we implemented in only six of the provinces; as of April 2003, only two provinces, Manitoba and Quebec, are not collecting data in ICD–10–CA. From a production point of view, we are maintaining three separate production systems in Canada because we collect ICD–9 data, ICD–9-CM data and ICD–10–CA data.

Let us review the goals of our redevelopment project. The re-engineering project was driven primarily by problems encountered in creating the 2001 version. The original database was built with an emphasis on supporting our production systems because prior to 2001, we had never actually published a Classification. Therefore, the goal of our data architectural review was to include all information required for the electronic publication in the database itself. In keeping with the new IT corporate strategy, it was decided to take the opportunity to port the sequel server VB 6 application that we had for Version 1 to our new tool set, which was an Oracle Unix platform with a browser-based Java application. The decision to include raw XML in the Oracle database allowed us to retain much of the formatting that would have been lost if the data were stored in simple text fields as in Version 1. We also added missing elements from the original model, and in revising the whole model, simplified it. We cut the number of tables by about half in the new version.

For modeling the Tabular List, all levels of categories were combined into one table, whereas in Version 1, we separated codes into a separate table from all of the levels above code, chapter, block and three-character categories. In doing so, we ended up with duplicate records because a code could also be a three-character category, which caused problems when we were trying to output our final products. So, we joined them all into one table with a hierarchical system that is a tree kind of functionality of parent-child; each record has a parent ID record within the table. We also have different levels, chapter and block. We have Block 1, Block 2, Block 3, and then levels of category from one down to the level of six-digit codes.

We added a code flag; the codes that are abstracted into our databases are flagged by the code flag equals ‘‘yes.’’ French descriptions were removed from the category table to a separate table, so that we could do an audit trail. If an English description was updated, we could say that the French description either was or was not updated. We tried to run audit-trail reporting at that level.

Coding inclusions, exclusions, additional code, and notes were stored as formatted data in one table using XML fragments in a data-type of CLOB. Complete XML documents, such as would appear at the beginning or in the appendices of the ICD were stored as files, another feature of the new database. These documents could only be edited by downloading them to the client PC.

Figure 1 shows the schema that we are using. We tried to make our database very generic, so we could load any kind of classification into it. In the Category table, we have ICD–9 codes, ICD–9–CM codes, ICD–10 codes, and ICD–10–CA in various versions. This allowed us to do validation when we were doing our cross-walking conversion tables. The Category table in the center of Figure 1 is the key table; it stores all the codes in a hierarchy. The ‘‘includes’’ and ‘‘excludes’’ are stored in category detail. The text table actually includes all of those XML files.

We also have a graphic table to store graphic images. For example, in our Canadian Classification of Interventions Product (CCI), we have a number of diagrams of anatomy sites that are in the final Folio product.

Figure 1. General Schema

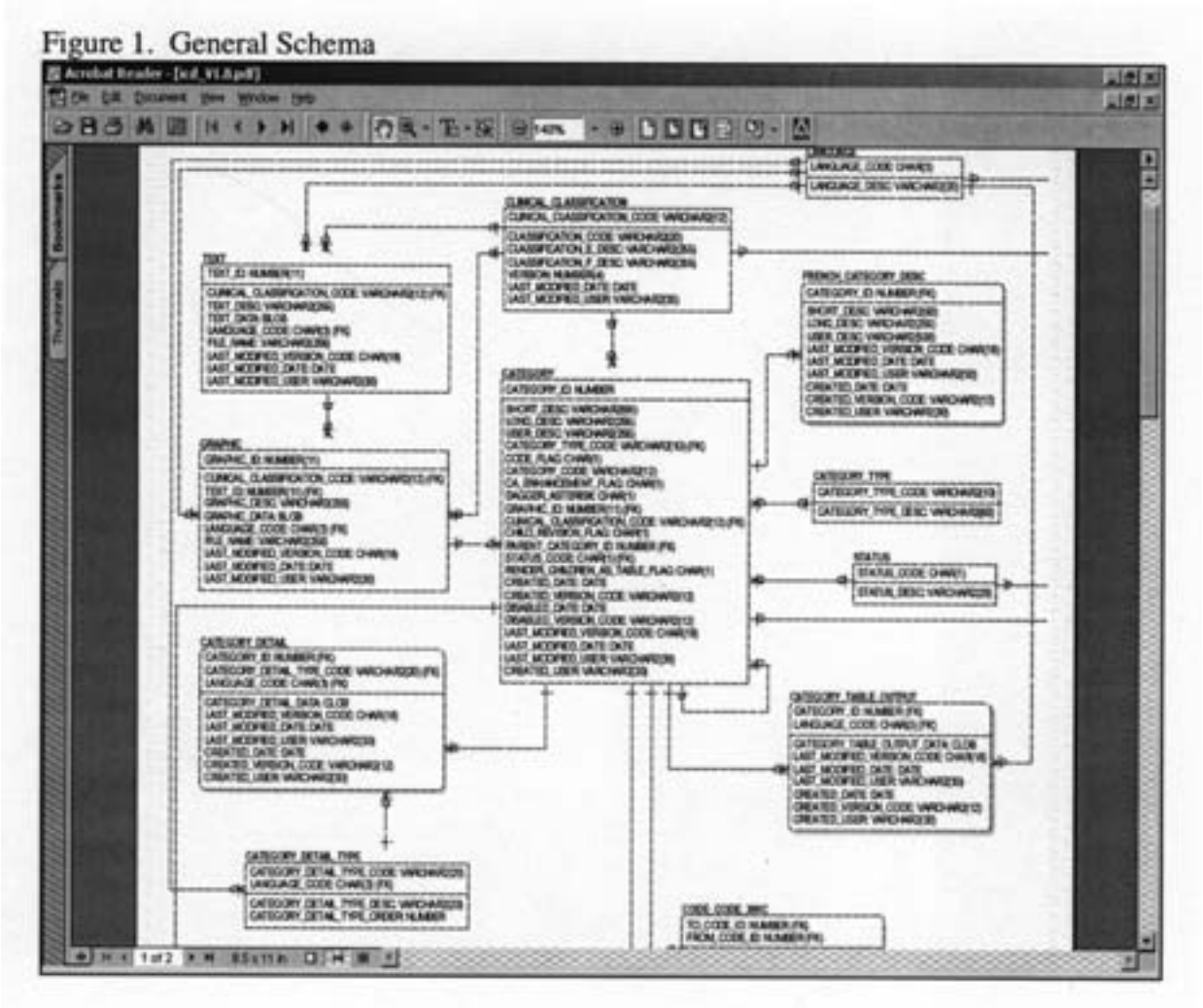
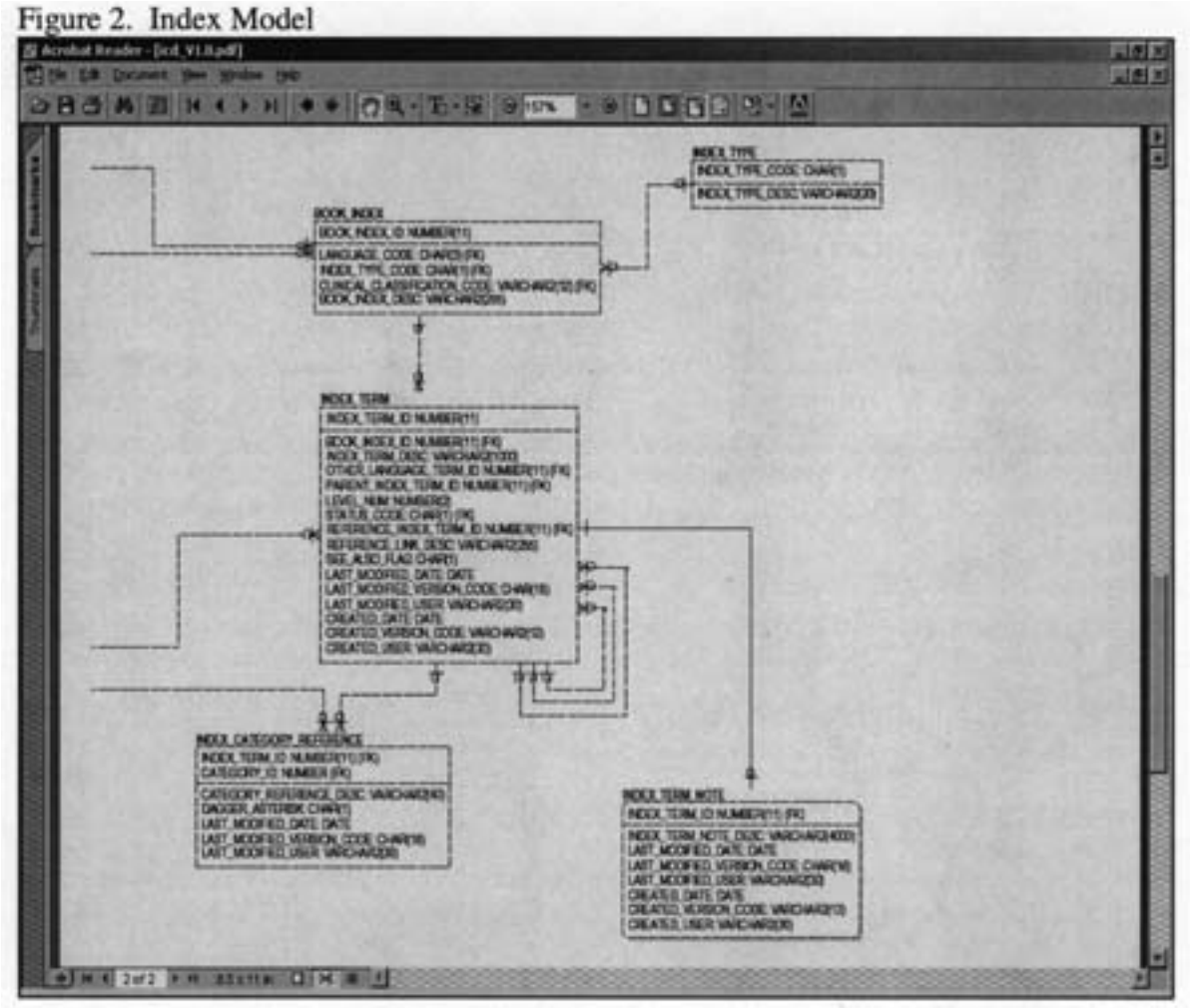


Figure 2 shows our index model, where we have the Book Index table, which includes the version, the language, and the index type. The Index Term table, which, once again, is a parent-child relationship, includes all the terms. The terms are by level numbers one to seven; a lead term would have no parent, and every term under that would have a parent term.

Figure 2. Index Model



We have a reference term—Index Term ID— which is to build our reference links to the CNC and to other terms within the Index Term table. We also have a ''see also'' flag that is either ''yes'' or ''no'' for ''see'' or ''see also.'' The hyperlink in the Folio product is rarely ever the actual index term that is in the Index; we have a separate description for that.

The Index Category Reference table includes the category ID of the code or multiple codes that will print in the Index, which facilitates validation to ensure that all of the links in the Index are actual valid active codes in the Category table. One of the improvements was the addition of an Index Note table, which had been overlooked in the first version of the database. We also stored XML notes and fragments in that table.

One of the revisions to the index model was the addition of a language code. In the original model, we had, for each row, an English and a French description; we found that this did not work well because they were not always the same or even on the same level. Instead, we created totally separate English and French indices, with links between the two. That resulted in having to do the maintenance of all of the links in both

English and French because the indices are now separate. Also, we added a dagger flag to the Index table because we found when we were publishing the Index that sometimes a code appeared as a dagger code in the Index, but not in the Tabular List; consequently, the dagger/asterisks flag in the Category table was no longer valid. We also pulled out the ''see also'' term description and the Index notes were added.

Let us discuss the French translation process. XML has been used extensively in the French translation process. The English 2001 XML documents were translated by Alpnet and used to load all XML fields in the new database. The category, conversion, and validation tables were loaded from the older version of the SQL server database. A similar process was used for 2003. We flagged everything that was either new or revised. We exported to XML and sent that off to Alpnet, which translated and returned it; we uploaded the database from it. Only the English changes were really done in the database itself. Because of the way we did the literal translation of the XML, when 2001 was loaded, it was very easy to link every English and French term, but maintaining those links for the 2003 version was almost impossible. To build this process, the entire Java application was slowed because we have drop-down lists of all the terms at a given level. The process also assumed that the English term and the French term would be at the same level, but for some terms that was not true. This will require work for the next version, in which we have to redevelop the Java application. As of the end of 2003, there are certain terms that are not linked.

I shall present some of the many problems encountered. In one of our loads from XML to the database, some of the French data got converted to UNICODE, and when we imported it into the Folio product, it was coming out as garbage. Consequently, we had to write scripts to go through our XML and correct that problem.

Some of the special characters such as ''oe'' and ''ae'' combinations of letters were not exported to Folio correctly and came out as garbage characters. Therefore, we changed them to the actual ''o'' and ''e'' characters, so that they would sort properly in the Index.

Sorting the French special characters, particularly if they were at the beginning of the word, was a real challenge from the automated point of view. Sorting of even the dagger code before the asterisks was difficult in Version 1 of the database because there was no way to tell that it was a dagger or an asterisks code. Adding the dagger flag to the Index made that a simpler process.

In Version 1, index terms starting with a numeric character did not come out anywhere. We repaired that problem so that they come out at the beginning of the letter ''a.'' For many of them, we solved the problem by taking away the numerics and spelling it out into words.

The process used for translation resulted in duplicate French lead terms, which is relevant to the admonishment in other papers about not doing a literal translation of the Index. Sometimes two or three different terms resulted in duplicates in the French, and in some cases, they even had different lower-level terms. Particularly in the CCI, in one case, four different lead terms were translated four different times; because they all had different subterms, we had to disable three of them and combine them into one.

I will discuss version control. Each year, after we finish the current version, we copy all the data and tables to a new version before we start maintenance. Users are not allowed to delete codes; all they can do is change the status from A to D for ''disabled.'' In that way, we maintain all codes in the database from the beginning of 2001 for all time. Since we have collected data for those codes, we can build evolution tables that will help us do trending over the years.

The new model includes the addition of a number of fields used for tracking changes to the database that were not there in Version 1. These include the day, the user, the version for creation of codes, disabling codes, and the last modified version. As a result, anything that was changed for this version can now be tracked. There are still some problems with that.

Despite the additions for tracking, we ended up with some problems. For example, a code was created and disabled in the same version, which means it was entered by error. That code erroneously showed up in errata addenda reports as being newly disabled and had to be manually deleted because the application would not delete it.

We trimmed back some codes, which resulted in problems. Some codes that we enhanced to a five-character level in Version 2001 were trimmed back to a four-character level; however, the codes were already in the database. They were not flagged as new because they had existed at a different level, but for users, they would be new codes.

Any field that changed in the category resulted in the record being flagged as modified, but it was impossible to identify which field was modified. For instance, we have three different versions of the titles: a short, a long, and a user version for the Folio product. For translation purposes, we would have to export all three because we did not have checks for each separate field. I am not sure whether we will actually move to that in the future.

When it comes to version control, our greatest challenge is with the final corrections made to the Folio product after the last database cut was taken. Some changes were made in the Folio Info-Base, but not in our database, resulting in out-of-synch version control. We are going to have to be very careful to make sure that our database matches before we copy it for the next version.

Another big challenge in publishing ICD is the way in which repeated information is displayed as bulleted lists or with a brace. For example, in the 2001 model, we stored each ''include'' and each ''exclude'' in a separate row in a table; when we exported the data, we used PERL scripts to try to recreate the ICD formatting. However, we found that no matter how many times we revised the scripts, we never came up with exactly the same look as in the ICD–10. That was one of the major reasons to move to XML; by storing the XML in the database, we could retain all of that formatting. Thus for the J10.8 code, for example, XML allows the brace to span more than one row to give the effect of the brace. Then we use the qualifier ''include'' and a ''U'' list to show the bulleted list underneath.

The biggest drawback to storing the formatted data in this way was the ability to identify which particular ''include'' or ''exclude'' had been added or modified. All we could tell from the database level was that formatted text had been changed, but we could not tell what was added or deleted. Thus, it got flagged as modified for that version.

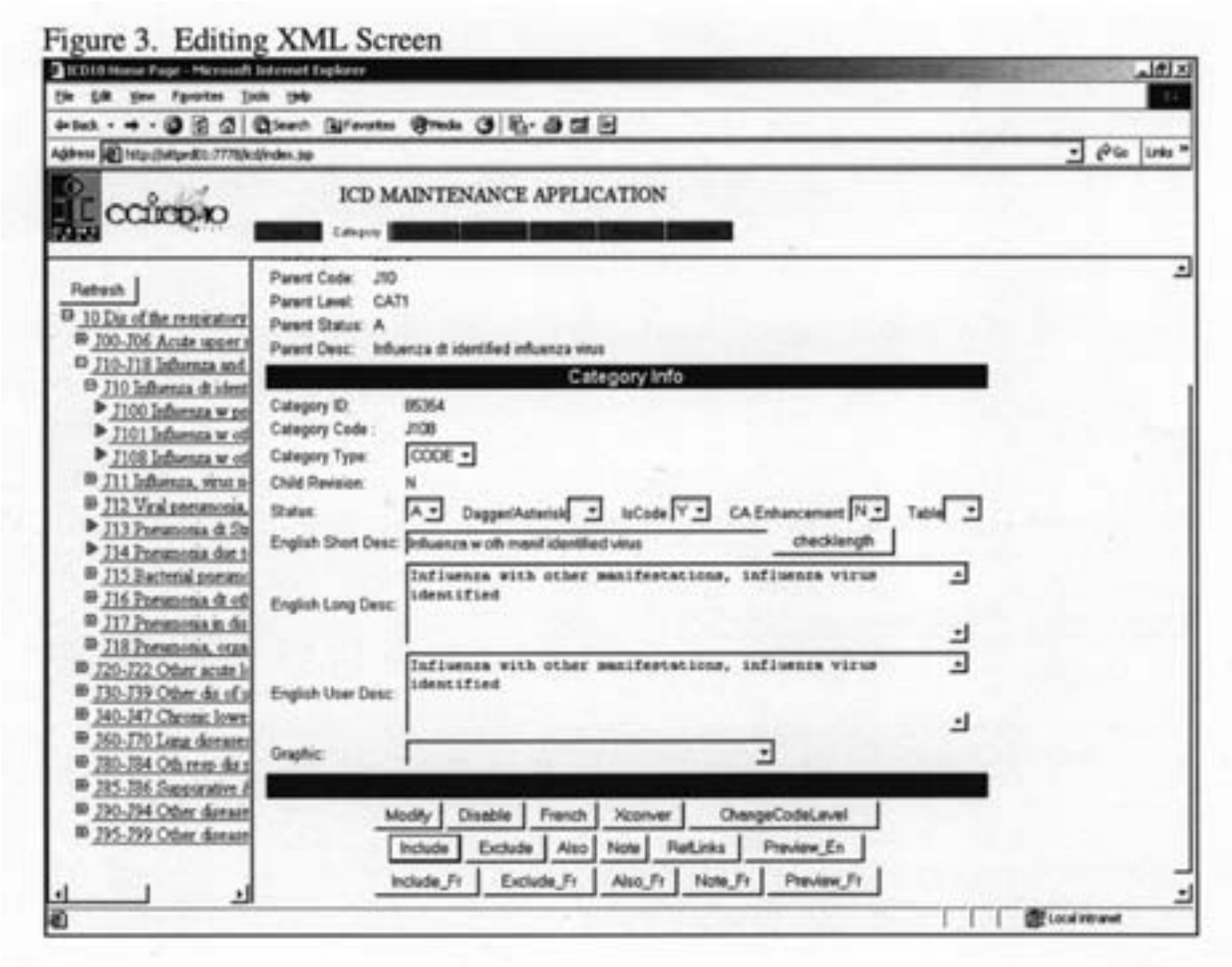
From the translation process, we exported the whole entire text to be retranslated.

On the application development side, a browser-based Java application was developed for editing the Oracle database. The application allows for two methods of editing XML fields. Complete XML files stored in the text table must be downloaded to an XML editor on the user's desktop. A customized application was developed in XML 3 to allow users to review their changes. An interface was developed using HTTP protocol to post the data to our Web server where the Java application validates any code links to ensure that they are valid before saving the XML files back to the database. The Java application also allows many of the XML fragments to be edited in a text box. So where it is just a fragment of text such as ''includes'' or ''excludes,'' they are actually editing the tags in the text box itself. The XML is parsed before it is updated to the database. XMETAL uses DTD to validate, and the Java application just ensures that the XML is well formed.

We also built a preview functionality that transforms the XML into HTML; so if the users are making changes in the text box, they can actually see the results of what they have done.

Figure 3 shows the location for editing the XML in the text box. In the main category you would first choose the version; then you would choose a chapter; from the chapter, you would build the tree in Java down the side of the application; and you would go down the tree to pick whichever code you wanted to modify and highlight it. All of the fields associated with that code would be filled in.

Figure 3. Editing XML Screen



The index application is similar, as shown in Figure 4. You must first choose English or French, then the index because in ICD–10, we have built four different indexes. After choosing which you want to modify, you can search for a word or a string of words in the lead term using a search engine that we provide. Given a lead term selected for maintenance, it brings up a list. For example, in Figure 4, ‘‘hernia’’ brings up a list of all the lead terms that have the word ‘‘hernia.’’ The user then chooses the appropriate term, and the program populates the tree down the side.

Figure 4. Editing Index Term

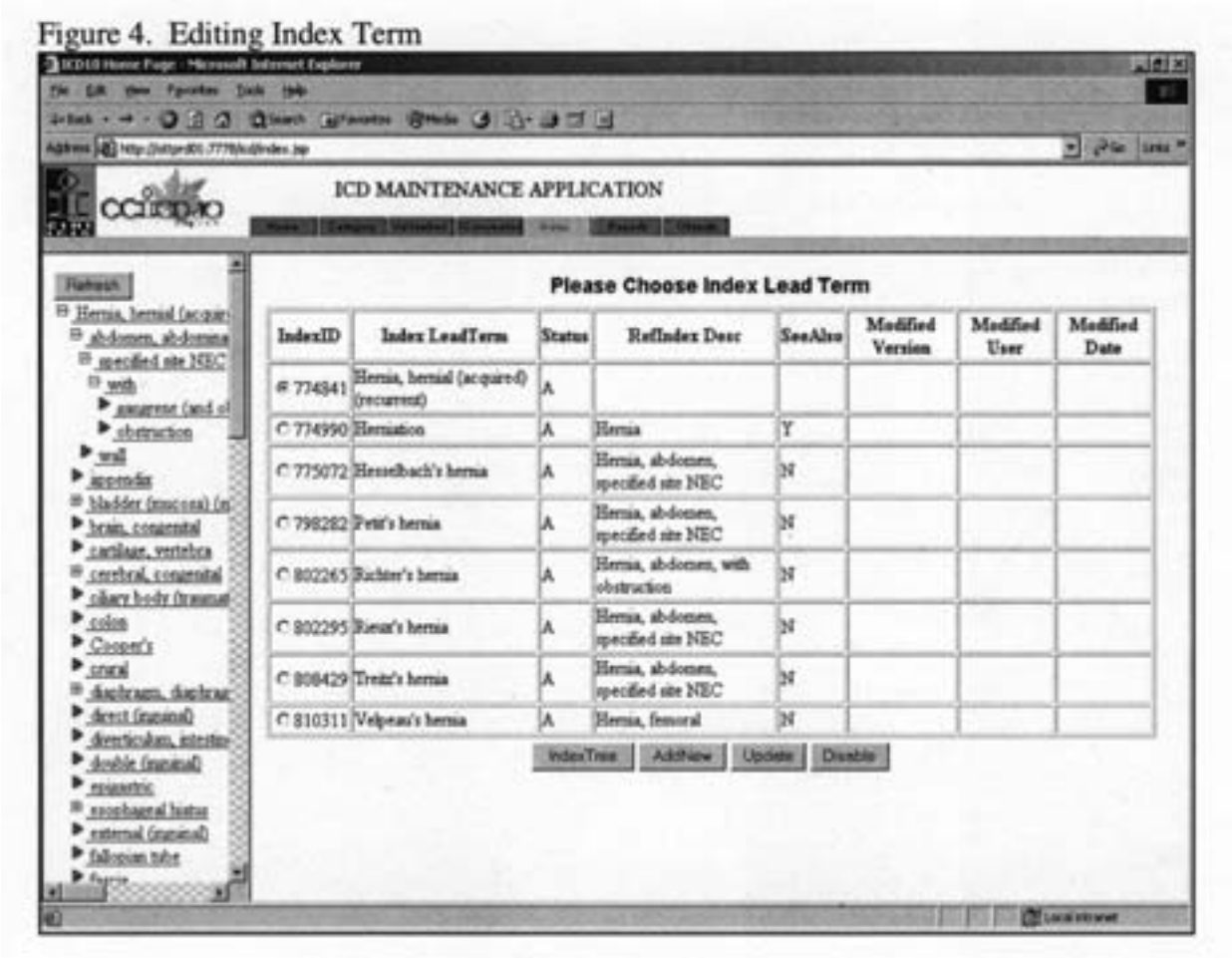
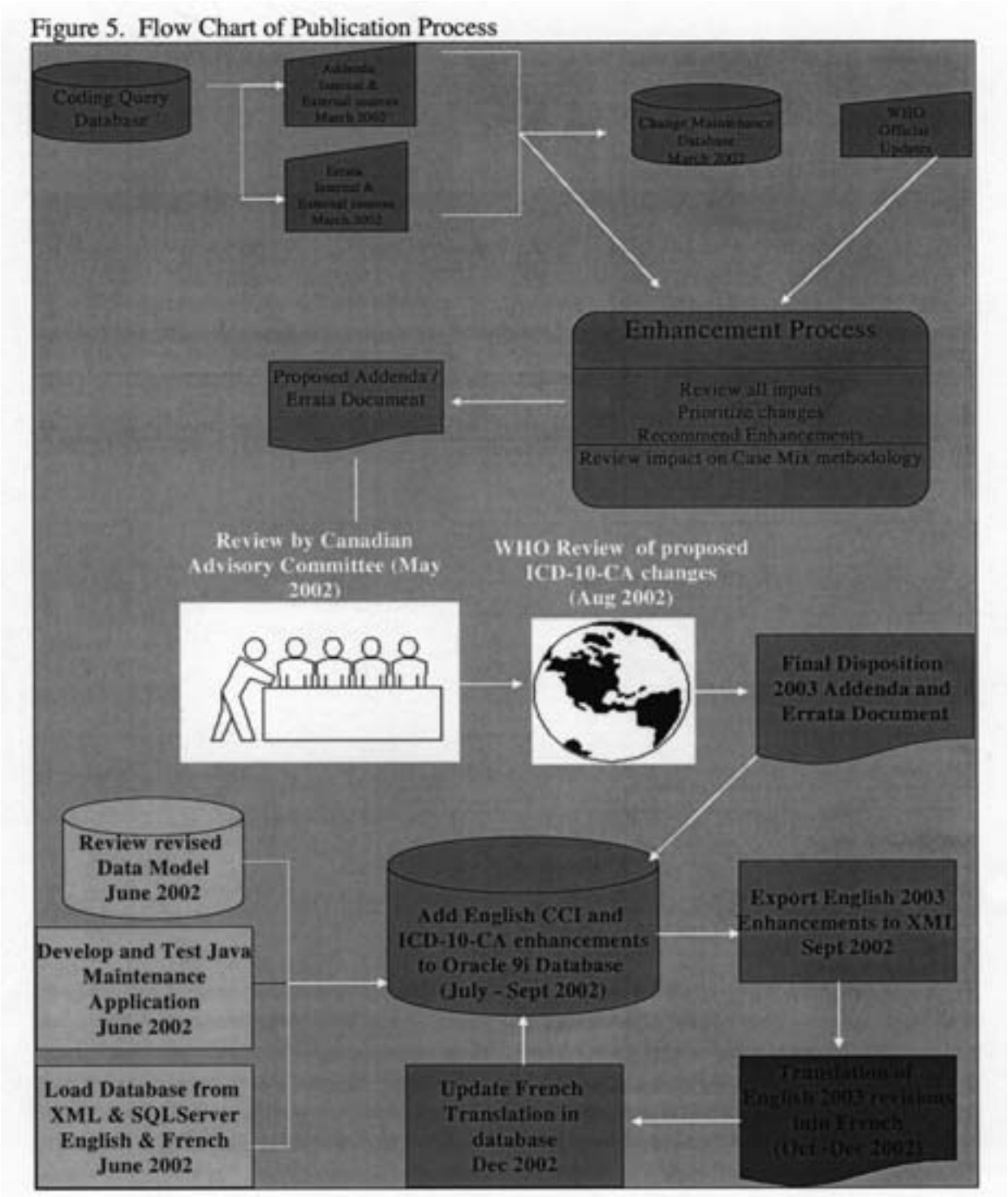


Figure 5 shows the flow chart of our publication process: we have a coding-query database to which our coders send in any enhancements, errata, or problems they have with coding. Much of our input into the enhancement process comes through that venue. All the WHO official updates go into the enhancement process, which is reviewed and prioritized. Then we create a document that goes to the Canadian Advisory Committee, which either accepts or rejects. Any changes to ICD–10–CA also go through WHO for approval, then we come to a final disposition. At that point, we make changes in the database in English. We export the enhancements out to XML. We send them out to be translated; the updated French comes back after about three months. Then we reupload into the database to make the changes.

Figure 5. Flow Chart of Publication Process



In our output process, we export the data and create an XML document that serves as a medium between our database and the actual output formatting. We create a Folio product as well as a PDF version in FrameMaker. It is an iterative process. When we get a Folio Info-Base back, we do quality assurance at the Classifications Department. When they find corrections, they recorrect the database. We export another version and send it off to Newbrook for creating the XML documents and the Folio, as well as the frame.

Discussion

M. SCHOPEN: Karen, one question. If you put the XML out of the database, can you know that you will get the database back?

K. HORNE: From the XML document, could we reload all the database? Yes, because although we did not really load the category table, it could be loaded from there as well.

M. SCHOPEN: Thank you. And, David, no curly braces?

D. BERGLUND: No, we do not have the curly braces, so those could not be readily regenerated, and that could be potentially an issue for publishing.

M. SCHOPEN: Anybody else?

PARTICIPANT: Let me thank the Electronic Tools Committee under your chairmanship that has organized this session and all the other work that you have done. I think it is an exciting time to see how the electronic tools are developing and enabling us to share information in the Classification. We appreciate putting this session into the ICE effort, as we can see how links could be established between this type of work and the mortality work; it is certainly the wave of the future. So I was wondering whether the Committee and the panelists could advise us about the so-called ICD-XM and the SuperMICAR database, which will merge, in a sense, the different vehicle modifications. While you have been skeptical about this, from the different approaches as outlined and presented, XML seems to be primed, at least from the beginning, for the XM approach. I was wondering about the feasibility of using XML as the way to go.

K. HORNE: I do not see any reason why the XML cannot be used. No matter what system we are using, I think that it certainly will be capable of outputting in that format.

M. SCHOPEN: I believe that XML is more flexible than the database, and it depends on the data you have to match. If the granularity is gross, you cannot do it in the database; if the granularity is very fine, XML is better. A disadvantage of XML is there is no indexing, and there are no consistency checks easy to implement. It is easier to handle in the database; that is why I think that the hybrid approach is the future.

PARTICPANT: I think that this know-how has to be documented in terms of its functionality, scalability, transferability, and costs. For example, if the mortality people would like to take the path of the morbidity people, it would be good to have some sort of a roadmap. We would do it for the primary care version or other versions. So the Electronic Tools Committee would be some sort of a powerhouse if you enable them.

M. SCHOPEN: So far, we are on the mark-up side, and we do only as SGML or XML whatever it is. We are rethinking our approach; a consultant with whom we discussed it said XML plus database. So there will be the knowledge in the near future, and we will keep track of what is happening there.

D. BERGLUND: I do think there is a lot to be said with embedding a certain amount of XML in the database for some types of formatting. Using a database alone, with none of the XML for formatting, you can lose some things such as subscripts. You might have something like B–12 and then wonder, ‘‘Is this a vitamin or is it a code?’’ Although we do not have a B–12, it might be a little confusing for an automated system that is trying to sort out what that would represent.

M. SCHOPEN: I completely agree. Sue, what are your experiences?

S. WALKER: This is not my area of expertise, so I do not really have anything to say, other than I certainly think we have the expertise with the XM versions to do something for maintaining and developing ICD–10, and I think we should move quickly to harness that expertise and use it.

ICD–10 Thesaurus: An Alternative to the ICD–10 Alphabetical Index?

Dr. Michael Schopen, German Institute of Medical Documentation and Information (DIMIDI), Germany

I wonder whether there are alternatives to the Alphabetical Index we have to ICD–10. In Germany, we have the ICD–10 Thesaurus as an alternative. I am going to give a brief presentation of that approach.

We have the printed Alphabetical Index for book readers for manual coding, and we have heard a lot about computer dictionaries for automated coding. We have to maintain both. The question is how can you bridge the gap? I shall say a few words about the present situation, international experiences, and the thesaurus for morbidity. Then I ask the question, ''Is this approach useful for mortality?''

We have seen the MICAR dictionary, 150,000 entries; the Italian dictionary, 178,000. When we discussed automated coding in Germany, the first reaction was, ''Well, we have to translate the MICAR dictionary,'' and then we asked the question, ''Do we really have to translate the MICAR dictionary?'' because that would mean a huge effort. Then we heard about the Swedish experience: less than 7,000 entries, but language standardization.

What is our experience with morbidity? We made a mistake for ICD–9; we translated the ICD–9 Index. We made a mistake for ICD–10; we translated the Alphabetical Index. Our doctor said, ''I do not find my diagnosis in this Index. I looked for urinary-tract infection and the only thing I see is 'urinary, see condition.' What does that mean?''

In 1996, we collected terms from hospital-discharge records and ambulatory reimbursement records, and we set up our very first thesaurus of those terms actually being used. It was tested in 1997 and updated three times afterwards. Now, it is a database with over 30,000 terms, and more than 60,000 searchable words in a book.

The problem with the book version, which is useful for manual coding, is that it is not a useful dictionary for automated coding; on the other side of the coin, the computer version is useful for automated coding, but not for manual coding. We asked, ''Is it possible to create the book version automatically from the computer version?'' In normal languages, it is; however, German is not a normal language. What we want is a computer version, ''chronically lateral kidney function disorder,'' and for the book version, we want, ''kidney function disorder, chronic unilateral,'' ''function disorder, chronic kidney unilateral,'' and so on. This is easy in English, but German is an awful language. Surely, there is not another language that is so slipshod and system-less, and so slippery and elusive to the grasp. One is washed about in it, hither and thither, in the most helpless way; and when, at last, he thinks s/he has captured a rule that offers firm ground on which to take a rest amid the general rage and turmoil of the ten parts of speech, s/he turns over the page and reads, ''Let the pupil make careful note of the following exceptions.'' S/he runs his/her eye down and finds that there are more exceptions to the rule than instances of it.'' This is true. Even the Germans do not know the rules, and they do not understand them. Some German words are so long that they have a perspective. Observe these examples: ''*Freundschaftsbezeigungen*.'' ''*Dilettantenaufdriglichkeitens-tadtverordnetenversammlungen*.'' These things are not words. They are alphabetical processions. And they are not rare. One can open a German newspaper at any time and see them marching majestically across the page.

Well, we cannot do that automatically. We have added some information to the text in the computer version, and what it says here is we have a noun phrase, an adjective, ''chronic,'' an adjective, ''unilateral,'' another noun phrase, consisting of ''kidney function disorder,'' and another nice feature of the German language, filled-in characters, which we use to glue the words together. These fill-in characters have few systematical rules; the ending, for instance, makes ''kidney'' plural and the ''s'' makes it genitive. It is really confusing, and the computer has problems to know what is what. Is it plural? Is it some character where it can split the word?

With this additional information, now, we can generate the text in an index format. How does the computer know this is an adjective? It cannot delete this inflection of character at the end. The computer knows, ''I can split near kidney function disorder. I can split it at 'near,' at 'function,' and at 'disorder,' and let me get the indented form.'' So the system is a learning system. Once you have tagged certain words, the system learns how to tag them and contains a function that helps you to do that automatically, by and by.

This thesaurus was applied to cause-of-death certificates. We were quite astonished that only 35 percent of the phrases on cause-of-death certificates could be coded with a thesaurus. Obviously, terminology is slightly different on cause-of-death certificates than on medical records. However, by adding about 1,000 phrases from cause-of-death certificates, we could increase this from 35 percent to about 80 percent. Still 80 percent is not enough for automatic coding, but it is better than nothing. So we have to collect texts from cause-of-death certificates to enhance this thesaurus, and this will be a collaborative project between the German Federal Statistic Office and the German Institute for Medical Documentation and Information. However, the funding of this project is still uncertain. As you all know, the Minister of Finance has taken away many resources from the budget, and, at the moment, there is no funding for this project.

Thank you.

Mortality Data in the German Health Monitoring System

Christiane Rosenow, Federal Statistical Office, Germany

I am responsible for hospital statistics and causes of death statistics at the Federal Statistical Office of Germany. The abbreviation for Health Monitoring System in German is GBE, which stands for ''*Gesundheitsberichterstattung*.'' My lecture will cover two subjects: 1) what the German Health Monitoring System is about and how it was developed, and 2) how you can find health data, in this case mortality data, within the system.

In 1987, 2 years before the German Unification, the promotion funds of the then Ministry of Research and Technology permitted the start of a project whose purpose was to take a stack of data sources and develop a proposal for a concept of future health monitoring. Many data sources in the health sector were found, but their output was uncoordinated and sometimes had no application whatsoever.

After some years of organizational and financial preparation, the main phase of the research project started in 1994 when research institutes, epidemiologists, data-processing experts, and data providers—coordinated by the Federal Statistical Office—worked untiringly to develop and implement the detailed concept. The result of this was the health report in text form, supplemented by more detailed reports on special issues. The search for a promising way to let the public know all about the manifold data and information pool resulted in the idea for an online data information system that brings together all the relevant information of the health sector in one database. The general aim of the project was to establish an infrastructure of health data that can be used in politics, science, research, and by the interested public to discuss questions on health. Financed by the Ministry of Health and Social Security and the Ministry of Education and Research, the ''Health Monitoring System'' started its routine work. It is now a joint venture of the Federal Statistical Office and Robert-Koch Institute.

The Robert-Koch Institute observes the incidence of diseases and relative risks of health in the population and scientifically explains the necessary arrangements to effectively protect public health. It monitors the health of the German population and coordinates the reporting system. The Federal Statistical Office operates the Center for Information and Documentation of Health Data within the Ministry of Health and Social Security. The GBE information system (IS-GBE) was released to the public on May 5, 1999. New releases were issued in May 2001 and February 2003. Completing and updating the system will be an ongoing and continuing process. Begun with 35 data sources in October 2000, there were about 100 data sources in the system by January 2003.

There is, of course, an English and a German version. The English version contains less information than the German, especially in the fields of texts; it may contain bugs because quality assessment has focused on the German version. All the information can currently be accessed free of charge, and there are some additional options, like an individual shopping basket for registered users. The IS-GBE contains about 650 million numbers from 100 data sources, about 300 ad hoc tables, 800 frozen tables, 320 illustrations, and documentation for about 200 data sources. It has indicators calculated on the basis of acquired data. It has lists of variables, definitions, information about the data owner, and the GBE print publications, which are not usually translated into English.

Now, let us see what one can do to find data in the system. If you have access to the Internet, you start by entering the name of the home page into the address bar, which is www.gbe-bund.de. You can select the language by clicking on a flag that appears on the screen. If you want to search for data, you can either write a key word (text string) into the provided field or you can search for a given topic. I will start with the search via text string using the icon ''search.''

You can put a text string into the provided field, such as ''mortality causes of death.'' When you write it in and press ''search,'' the system starts and provides a little list. In this case, the system found 30 tables, no diagrams, no texts, no definitions and no other documents. If you click on ''tables,'' a hit list will appear sorted in alphabetic order. Scrolling further down, you will find mortality. Suppose we are interested in mortality from 1998 onwards because it is coded in ICD–10. You select that and a new window opens

containing a very small table, with the numbers for three groups from 1998 onwards until 2001. The big advantage of IS-GBE is its flexibility to show data adapted to the users' needs; the system offers possibilities to change values into what is individually needed. The changeable variables in this example are region, age, sex, and nationality. You can choose all nationalities, German, non-German, foreign, state-less, or unknown. It is also possible to choose the region, that is, Germany as a whole or one of the states like Bavaria, Saxony, and so on. You can choose male, female, or both sexes; you can choose all age groups or individual age groups (by 5-year increments). Additionally, the system offers the possibility to subgroup (if you click on them) by ICD codes at the three-digit level. Let us suppose that a user selects German nationality, the region of Bavaria, male, the 25–30 age group, and then sub-groups by ICD code. To download the resulting table, he would click on the ''basket'' icon for shopping basket; a new window would open and show a table that could be downloaded in PDF or Excel format.

The other option is to do a search by topic. If you click on the icon ''topic,'' you will get a list of ten main topics. If you choose ''health status'' as main topic, you get the subtopic ''mortality,'' which will then generate ''causes of death.'' Selecting the latter will generate a hit list containing 109 tables, 37 diagrams, no links, no text, no definitions, but 8 other documents, including information about data sources, data owners for this statistic, a person to contact if you want some more information on mortality data, information on the purpose of the data collection, legal base, data collector, reporting stations, object under review, collection, processing, publication, comparable data sources, remarks, and the last update. All the information you need for this special statistic is in the system.

In summary, the content of the system includes standard services like general information, news board, e-mail facilities, and online help. You can search for health data by either selecting one of the given topics or typing in a key word (text string). Both will lead to texts, frozen tables, frozen graphs, or ad hoc tables. One can view the frozen tables or modify the ad hoc tables and then store them. There are storing facilities like a shopping basket where one can put all those documents. One can also delete them and, of course, download them.

Thank you all for your attention.

Questions

M. SCHOPEN: Thank you. All that is free of charge?

C. ROSENOW: Yes, free of charge.

M. SCHOPEN: Any questions for Christiane Rosenow?

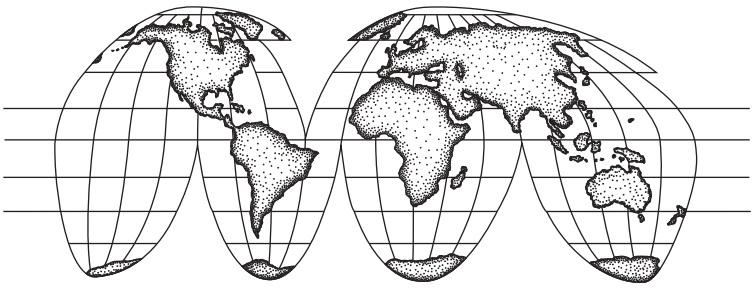
E. JOUGLA: How do you manage with the confidentiality problems?

C. ROSENOW: That was my problem just yesterday. The data in the system is checked, so the only data made available is data with no problem of confidentiality. If there is a confidentiality problem, the information is not released, and the user will see a note that this is information we cannot give out.

S. NOTZON: My thanks for an excellent session. I think we have all been appropriately warned now about the dangers of preparing one of these clinical modifications.

SESSION 6

Training



Session 6: Training

Ron Casey (moderator), Australian Bureau of Statistics (ABS), Australia

I suppose all of us here who are responsible for mortality coding using automated systems have a large issue that we have to deal with: training. Not only do we need to train our own staff in the automated mortality systems, but we also need to train our coders in ICD; we also hope we can influence certifiers by helping to train them so that they can provide us with better quality information on cause-of-death certificates.

We are going to have presentations on all three of those subjects: Tyringa Ambrose and Julia Raynor from the National Center for Health Statistics will talk about multiple-cause coding with the MMDS System; Dr. Roberto Becker from PAHO will demonstrate INTERCOD, which is a electronic tool that provides ICD training in a number of languages; and Monica Pace from ISTAT, the Italian Statistical Office, will tell us about a certifier training package that her office is developing for the European Union.

You have probably already heard at this meeting a number of references to the WHO Heads of Centers Training and Credentialing Subgroup, which was established in 1999. The chair of that subgroup, Marjorie Greenberg of MCHSC, is here today, and she will start this session by giving us an update on the subgroup's progress and activities.

Update of WHO Training and Credentialing Group

Marjorie Greenberg, WHO Collaborating Center for the Family of International Classifications for North America, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

I will tell you about the context in which our group does its work, which is the WHO Collaborating Centers for the Family of International Classifications, and then review the objectives of our subgroup and our progress with each one.

In the Family of International Classifications, the flagship classification of long-standing use and relationship to WHO, is the International Statistical Classification of Diseases and Related Health Problems (ICD). Complementary to ICD is the newer International Classification of Functioning, Disability and Health (ICF), which starts where ICD ends and looks at consequences, to some degree, of health conditions and injuries and illness. Then there are a number of adaptations and associated products, such as the ICD–O. Our subgroup is for the entire family although most of our work at this point has been done for ICD.

ICD and ICF are maintained by the WHO with this network of collaborating centers, which have been established based on language and geography (initially language, but then geography as well). Around 1976, it finally was determined that the U.S. does not necessarily speak the same language as the U.K. That was when our collaborating center, the North American Collaborating Center, was established. We are responsible for the classifications in the U.S. and in Canada. In that capacity, I work closely with both Statistics Canada and the Canadian Institute for Health Information. We meet annually with WHO to advance our mission, which is to develop, disseminate, implement, and update the classifications in order to support national and international health information systems, statistics, and evidence.

The Training and Credentialing Subgroup was established in 1999 as part of the implementation of the ICD–10 Committee, which has now been renamed the Implementation of the Family of International Classifications Committee. When this group was formed, it recognized the importance of training for the successful implementation of ICD–10, for assuring comparable international statistics, and for calling attention to the profession and the skills required for medical coding and leading to some type of international credential. This responded to the recommendations of the first ICE. I would say that I probably ended up as Chair of this group because it is impossible to say ''no'' to Harry Rosenberg. This was very important to Harry, and he asked that I advance this in the Collaborating Center network, particularly as we were developing a work plan. The ICE called attention to the issues related to coding that Sam mentioned yesterday: that in an automated environment you may not need as many coders, but you need more highly trained ones who can deal with rejects and also change and modify the systems, etc.

At the second ICE, when I presented our plan to become a group and our terms of reference, several participants asked about countries that do not use automated systems. For manual coding, they also had a great need for raising the status of coders, for training coders in a standardized way, and for credentialing. So we expanded our agenda to include automated and manual systems, mortality, and, eventually, morbidity because when people found out what we were about, they noted a great need for this in morbidity, too, in most countries. While a small number of countries have a more established profession for morbidity coders, quite a few do not.

In any event, we have held meetings at each of the Collaborating Center meetings. Other than that, we conduct most of our work through e-mails and conference calls. We do have a list serve. We welcome anyone who is involved with the Collaborating Centers—or anyone else who is very interested in this subject—to participate.

After our formation in 1999, the first thing we did was inventory the kind of training materials available. We surveyed Collaborating Centers and regional offices in 2000–2001 to identify training materials and assess the capacity of the centers and offices to deliver this training. The results of our inventory are on the subgroup home page, which is part of the NCHS classification home page. In these inventories, we found quite a number of training products available at a reasonable cost in several languages that most developers would

allow to be translated into other languages. Most were paper-based, but many had plans for Web-based products. Because some of those plans have now been realized, we need to update our inventory. The Collaborating Centers and regional offices also reported a fair capacity to train coders and other trainers. ''Train the trainer'' courses were particularly seen as important to multiply the effect, as some people refer to it.

The other thing we wanted to do was a needs assessment to find out the need for coders and the training currently being given to these coders. So we initiated a needs-assessment questionnaire. This was somewhat more complicated because it had to go to the individual countries; the collaborating centers or regional offices did not have the information we sought, except for their own countries. The Pan American Health Organization (PAHO) was very helpful in translating those questionnaires, at least into the languages with which PAHO deals. We heard from 27 countries on mortality and about the same number on morbidity. We did confirm from that sample that the job titles and educational levels of the staff responsible for ICD–10 mortality coding varied tremendously. Most of the people had been trained on the job, rather than through formal training programs. Involvement of physicians in coding varied quite a bit by region, as some of you know. We are very keen on training certifiers on the certification of cause of death, and we are following that very closely. We are less enthusiastic about physicians or clinicians doing their own coding because we do not feel that that results in standardized information.

In many of the countries that reported, we learned that the coders have other responsibilities as well, including data collection and analysis. We found out that there are a variety of training materials used reflecting, of course, the languages needed. We also found that very few credentialing schemes exist. We asked and found that quite a few countries reported that the number of trained coders was not adequate. We are now revising these questionnaires to make them somewhat more user-friendly and plan to circulate them again in 2003. If you have not already responded in the first round, we would really appreciate your response. We are trying to respond to a need out there, which is needs assessment. One of the things we are going to ask in this revised questionnaire is whether it would be helpful to you if there were an international curriculum, that is, a standardized core curriculum as well as international credentialing for mortality coders and for morbidity coders as well.

As I said, the credentialing idea was one we were interested in from the beginning, so we developed an international proposal for an international training and credentialing program, initially for mortality coders, and, then, because of the interest, for morbidity coders as well. We recognized in that proposal the unique issues related to manual versus automated coding and underlying-cause versus multiple-cause coding. We presented this proposal to the International Federation of Health Record Organizations (IFHRO). Sue Walker, one of the members of our group, is active in IFHRO and was able to facilitate that. IFHRO had not really had much experience in dealing with mortality coders, but had a lot of experience with morbidity coders. At their 2000 meeting, they basically accepted this proposal in principle, indicating that they would be involved with this international effort, and formed a joint workgroup.

We have now identified three phases. The first phase is directed to the underlying-cause-of-death coders. The second phase is morbidity coders, and the third phase is the multiple-cause-of-death coding. This is because there are standards for underlying-cause-of-death coding, so we felt that we could move ahead with core curriculum and credentialing. We cannot really do that for multiple-cause coding until there is international agreement on standards for multiple-cause coding. We are looking to this group, the ICE, to help us reach that goal. Our second phase is the morbidity coding because ICD–10, Volume 2, does have a standard for morbidity coding.

The plan is that IFHRO would oversee the annual exam and could also certify essential courses. However, I should point out that IFHRO is a voluntary organization, made up completely of volunteers; it does not have an infrastructure that can do this independently, so that is something which we will examine more closely.

If we are going to move towards credentialing to establish this profession more clearly in the international arena, we need to have definitions, skill levels, and functions. For underlying cause, multiple cause, and morbidity, we have developed definitions, skill levels, and functions for entry-level,

intermediate-level, and advanced-level coders. We have also defined the nosological level because we feel that it is very critical for this work. However, our recommendation, at this point, is that credentialing would be at the intermediate and advanced levels.

The last thing that we worked on is the beginning of a core curriculum comprising the key educational needs for mortality and morbidity coders. We found that the morbidity coders think it is harder to do morbidity, and the mortality coders think it is harder to do mortality; some people think underlying-cause coding is harder while others think it is multiple-cause coding. Despite all of those differences, we decided, at the end of the day, that about 80 percent of the training needs were the same.

We identified 10 basic areas; our thinking is that we shall use a kind of modular approach. We will not necessarily come up with complete training materials on any or all of these, but we will have existing training materials assessed against these modules and then try to fill in where modules or training content does not exist. The ten areas are as follows:

- 1) resource materials and essential references needed by a coder,
- 2) knowledge of basic medical sciences,
- 3) privacy and confidentiality principles as they apply to the country in which a coder is working (because we know they can differ quite a bit),
- 4) purposes for coding,
- 5) uses of underlying-cause-of-death, morbidity, or multiple-cause data,
- 6) users of the data,
- 7) a module on the ICD, including the history, structure, and updating (a number of training products already include some of this),
- 8) discussion of the source documents that will be coded,
- 9) how to code, which is central to the course, and
- 10) a quality-assurance module.

Some members of our group are going to modify the core curriculum for morbidity coding; others have volunteered to prepare a paper for our upcoming meeting in Cologne in October 2003 on how to develop an exam that will lead to an international credential, using the expertise of members who are experienced in developing exams. We will also ask those who come to the meeting in Cologne to bring existing exams in their own languages so that we can initiate a process for developing the international exam. Our subgroup or committee is also committed to developing a brochure on these training and credentialing activities that we shall post on our Collaborating Center Web sites. Hopefully, the regional offices and WHO will also post it. We shall also have it in hard copy. We are trying to be cognizant of the fact that not everybody is in an automated environment, and we are also trying to deal with some of the language issues. PAHO has been very helpful, and we may be reaching out to others of you to translate some of our materials for your own language speakers.

We are now trying to receive feedback from the Collaborating Centers and from IFHRO. In addition to Sue Walker and a member of my staff, who participate in IFHRO, we have one very active IFHRO member now at the American Health Information Management Association. We are hoping to draw more people from IFHRO as well as stakeholders in other countries. We are looking to all of you who are not already participating to give us your feedback.

We hope to continue our work in Cologne and then to have another stand-alone meeting next spring, which is essential because we are pointing towards the 2004 IFHRO meeting to be held in Washington, DC in mid-October. IFHRO only meets every four years, so we cannot miss this window of opportunity. We will bring back to them the work that we have accomplished, get their buy into that, and initiate discussions with them on how to establish the infrastructure for international credentialing and training.

That is what we have accomplished to date and what we hope to accomplish in the next year-and-a-half. For this to be a truly international effort, we need very wide participation in our work, which will be helpful to our common interest of improving the training and profession for coders.

Thank you very much.

How to Become a Multiple-Cause Coder

Tyringa Ambrose and Julia Raynor, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

I am Tyringa Ambrose of NCHS. I am a member of the training team that is based in Research Triangle Park, North Carolina. We have been asked to address what it takes to develop the skills necessary to be considered a multiple-cause coder. There is a need in the United States for this ability, and this presentation will describe the method that has proven successful for us to meet that need. Our training package has three main parts: preclassroom, classroom, and postclassroom.

The pre-classroom materials include two programs, Basic Anatomy and Medical Terminology, which we call Book 1, and Introduction to ICD–10 Coding, which we call Book 2. Before students come to class, they need some knowledge of human anatomy and they need to be familiar with medical terminology. The first part of the pre-classroom training satisfies this requirement for us. While some of our students do have previous medical background, others do not, so this is a very important part of our training. It is a self-guided, interactive tool providing a general overview of anatomy and physiology, followed by a more in-depth look at each of the major body systems. The students answer frequent questions throughout the instructional material and receive instant feedback on their answers. Students are allowed two tries before an answer is actually provided for them. It is also necessary for students to have some knowledge of the international classification of diseases (ICD). The Introduction to ICD provides a brief historical background, as well as some elementary instruction and practice on finding medical terms in Volumes 1 and 3. As with Book 1, students are given two opportunities to enter a correct answer, and immediate feedback also lets the students know if they are correct. Students find the self-guided interactive learning tools very helpful as they progress toward the goal of becoming a multiple-cause coder. A pre-classroom quiz that the students must complete successfully is a prerequisite for admission to class. This helps ensure that each student has attained a certain level of knowledge, and it allows for our class time to be spent more productively.

Successful completion of the pre-classroom materials is followed by a two-week classroom session. Remember that at this point the students will have already worked through two CDs on their own, spent several hours in self-study, and even completed two tests before even beginning the multiple-cause instructions. Once the students arrive for class, they are provided with what we feel is one of the most important tools for multiple cross coding, which is the 2–B Instruction Manual. This manual contains the instructions necessary for accurate interpretation of data and proper assignment of multiple-cause codes. It is updated annually as our staff continues to perfect and improve its contents. During the two weeks of class, participants will study over 400 pages of instructions and will perform hands-on application of these concepts by coding almost 400 examples. The classroom session is a very intensive learning experience. Trainers must adhere to a very strict schedule in order to cover all necessary topics. Even with the rigorous daytime schedule, students are still expected to complete homework assignments throughout the two weeks. For our international students, class time is extended to three weeks to accommodate any language difficulties. An added element for the international groups is that we are training students who will go back to their home countries and, in turn, train others. Therefore, it is considered a ‘‘train the trainer’’ course.

Upon completion of the classroom session, the student moves on to a rigorous testing process called the Training Decks. A deck is a number of examples organized into a group or set for the student to code. A deck may contain as few as 10 examples or as many as 300. The Training Decks are divided into 21 different topics, each topic containing either three or four decks identified by A, B, C or D. Each deck has its own acceptable error rate based on the difficulty of the topic, as well as the number of examples included. At a minimum, all students are required to complete each of the A Decks. If an acceptable error rate is not received on a deck, the student continues on to the next lettered deck until an acceptable error rate is achieved; at this level of training, the student has only one chance to enter the correct code. Instant feedback is provided in the form of explanations that direct students to the proper instruction in the 2–B Manual.

After the student has satisfactorily completed each of the Training Decks, they progress to the last phase of our training process, the Qualification Deck. The Qualification Deck contains over 1,000 records arranged

in random order, much as a coder would see in a typical office setting. The coder must be able to locate and apply the proper instruction within the 2–B Manual, earning an acceptable error rate in order to qualify. The error rate on the Q Deck is based on a statistically weighted scale, such that the conditions reported more often are given greater priority than those that are seen less frequently. Unlike the previous training, the students receive no feedback on the Q Decks until they have completed them and the data file is sent to NCHS for processing. Once the error rate requirement has been satisfied, the student is deemed qualified as a multiple-cause coder, receives a certificate of accomplishment, and begins coding live data. As you can see, there are a large number of materials involved in the training of a multiple-cause coder. There is, however, an additional element, that being the students themselves.

I am going to turn the podium over now to one of our senior nosologists, Ms. Julia Raynor, who will address the topic of the human side of multiple-cause coding.

MS. RAYNOR: Thanks, Tyringa.

Training a multiple-cause coder involves the materials that we have talked about, but it is also important to remember that multiple-cause coding requires a special kind of person. A person who is well-suited for this type of work gives keen attention to detail, has a good memory, has good study and research habits, and has the ability to interpret and apply instructional data accurately. The ability to work independently is also desirable.

As you have seen, getting through the long process of qualification requires plenty of patience and determination. The students who do follow through with the entire program usually do well. The process is so long and intense that many students get discouraged and weary of the effort. They either move to different departments within the agency or opt for a different career completely. Oftentimes, they are attracted by better pay and shorter, less strenuous training periods.

Even after the student has completed the training package, there is much knowledge to be gained in working in the changing field of medicine. Career coders who have been working with medical data for many years confirm they continue to learn new things. The training office understands there is no substitute for experience in the field of nosology. So while the training package itself is a critical part of becoming a multiple-cause coder, truly, it is only the beginning of a career-long learning process.

Recognizing that the newly-trained coder is inexperienced and that there is still much to be learned brings to light another issue. With the benefit of the automated system, a large percentage of the records are handled electronically. The most difficult records are rejected for manual-coder review. The nature of the work demands a high level of knowledge, even though the coder has minimal experience. Automation has brought about an increase in the need for coders who are better trained. The efforts of the Training and Credentialing Committee are very much appreciated because of this. As mentioned previously, students who persevere and work through the entire training program usually do well. This is the system that has been used for many years in the U.S. and has proven to be successful.

To make our classroom time more effective, NCHS at Research Triangle Park is developing a new electronic training package involving the 2–B Multiple-Cause Coding Manual. It will be on a CD and will lead the student step by step at their own pace through the topics relating to coding of diseases. Coding examples and quizzes will be provided along the way, giving assurance that the student attending class for the first time will be much more knowledgeable about the international classification of diseases and will already have some experience with the coding instructions. The hope is that the formal classroom time can be reduced from the present two weeks to one week and that week can be devoted to the most complex instructions, such as complications of surgery, medical care, drug poisoning, and so forth. The training staff is working diligently on the automation of the multiple-cause coding manual and looks forward to its completion. We believe it will be a welcome addition to the total NCHS training package.

Thank you very much.

Demonstration of INTERCOD

Dr. Roberto Becker, Pan American Health Organization (PAHO), Washington DC, U.S.

Note from the editors: This was a live interactive presentation of a software program on a laptop computer.

Some of you may have already seen the demonstration of INTERCOD in Brisbane, Australia. This system was developed in Mexico at the National Classification Center, with participation of the National Committee on ICD from Argentina, the Venezuela Center, and PAHO. It was released at the end of last year.

The basic menu covers ICD with background on the importance of ICD, purpose and applicability, and parts of Volume 2. The text is not exactly the same as in Volumes 1 and 2; it is adapted and, in some instances, expanded. The trainee can then navigate through the system.

The system also shows the basic sources of data. It covers both mortality and morbidity, according to what is in ICD–10 for both. That means selection of underlying cause of death and main condition as defined in Volume 2. It describes how to record causes of death on the international medical certificate of cause of death. We have examples of the death certificate for almost all the countries in the Americas. Some parts of this software require having Acrobat Reader, but if someone does not have it on his or her computer, the CD-ROM comes with Acrobat, so it can be installed.

The next module is coding. Here, we have all the steps discussed: how to use Volumes 1 and 3 because, basically, the training is in Volume 3. So the contents are discussed volume by volume, and we also have exercises. Look at the question, for example, ‘‘What are the inclusion terms of A07.3?’’ and so on. The trainee needs to have all three volumes with him or her.

One may also surf through the menu, directly jumping to another topic. For some pages, one needs to scroll up and down and so on. We have other functions in this software such as anatomy training. The software also has a Help section with an overview of the system.

At the end, one is presented with a complete evaluation, topic by topic, with many questions, not only coding questions, but related to all topics covered. Almost all the questions not only tell the user whether they answered correctly or incorrectly, but the right answer is provided in a complete statement. The user can follow his or her own progress.

Another one of the resources is a glossary of 44 pages of terms, prefixes, etc.

Thank you.

Discussion

S. WALKER: My question is if some region wants to have NCHS come over and organize training for some region, for example, southern Africa, is that feasible?

J. RAYNOR: We have had some international classes. The ones that we have had so far have been in the U.S., and we have invited other countries to come to triennial sessions. So you might be interested in that. If your interest is in NCHS conducting a course in another area, then I would say the person to contact is Donna Glenn.

L.A. JOHANSSON: This is a question for Becker. Do you have any plan to update the code or keep track of the updates to the ICD? I could not help noticing that you have the old version of Rule A, which has been expanded to cover more conditions than in Chapter 18.

R. BECKER: Yes, I did not show the many updates; this is Version 1. We are waiting for some feedback to make adjustments, improve, and include the updating being done in ICD–10.

Preparation of EU Training Packages on Certification of Causes of Death

Monica Pace (presenter) and Silvia Bruzzone, Department of Social Statistics, Italian National Institute of Statistics (ISTAT), Italy

Quite recently, Eurostat, the Agency for Statistics of the European Commission, made a call for tender (request for bids) to create a training package to improve quality of certification of causes of death in Europe. Italy now has the opportunity to develop this project. In this presentation, I am going to show you something about this project of which we are in the early phases. The project began in January of this year with duration of 18 months. The participating countries to this project are the 15 European Union Member States (EU 15); countries of the European Economic Area / European Free Trade Association (EEA/EFTA); and Central and Eastern Europe countries (CEEC), including Candidate countries and Western Balkan or ''CARDS'' countries (see Table 1).

Table 1. List of Participating Countries to the Project "Preparation of an EU Training Package on Certification of Causes of Death."

CEEC Countries: a) Ten accepting countries after enlargement negotiated in December 2002 (formerly candidate countries): Cyprus; Czech Republic; Estonia; Hungary; Latvia; Lithuania; Malta; Poland; Slovak Republic; Slovenia b) Three Candidate countries not included in the enlargement: Bulgaria; Romania; and Turkey c) Five Balkan countries (''CARDS'' countries): Albania; Croatia; FYR Macedonia; Bosnia Herzegovina; Former Federal Yugoslav Republic: Serbia and Montenegro
EEA and EFTA countries: Iceland; Norway; (Liechtenstein); Switzerland + EU
EU Countries (EU 15): Austria; Belgium; Denmark; Finland; France; Germany; Greece; Ireland; Italy; Luxembourg; Netherlands; Portugal; United Kingdom; Spain; Sweden

The aim of the project is to develop a common standard European training package for certifiers providing tools fulfilling the WHO and Eurostat cause-of-death task force guidelines and recommendations on good certification practices. After the development of these products, each country will be responsible to adapt them to its own certificates forms and certification practice. The background for the present project is based on the results of a previous project EU-DG SANCO–EUROSTAT ''Comparability and Quality Improvement of European Causes-of-Death Statistics'' prepared under contract for the EC by CépiDc–INSERM (F). As a result of that project, the Eurostat Task Force on Causes of Death issued a set of recommendations on certification practices that form the basis of the present training package requirements.

To summarize the main aspects of these recommendations, I would like to focus your attention on a few aspects such as:

- Training should be addressed both to medical students and physicians;
- Training should be performed at the end of clinical training as part of appropriate academic courses;
- The contents of the course and exams should be prepared by cause-of-death (COD) Statistics Offices in collaboration with university teachers;
- Training opportunities for physicians should be included in ''continuing medical education'' programs;
- COD Statistics Offices should take advantage of opportunities for informing doctors on death certification via: queries, medical and public health journals, conferences and congresses for physicians;
- The training package should become a generalized reference on certification, further adapted by each European country.

The undertaken actions comprise so far:

1) Setting up a steering board that includes representatives from various countries;
2) Updating the available information on training practices and some related issues by means of a questionnaire sent to all the 40 participating countries listed in Table 1. In particular, we are focusing on 51 questions dealing with death certificate, infant death certificate, certification practices, confidentiality, coverage, and ill-defined conditions. The questionnaire is based on a selection and an updating of the 182 questions submitted in 1999 during the project ''Quality and Comparability Improvement of European Causes-of-Death Statistics.''
3) Reviewing the existing information about certification practice and structures of certificates in all these countries;
4) Updating part of the questionnaire used in the project on comparability and quality improvement;
5) Reviewing the existing training manuals, Web sites, and other resources on causes of death certification.

There are three expected outputs of this project. The first is a manual on certification in two languages, English and French, with a strong emphasis on good certification practices. The importance of getting good data on mortality for epidemiological purposes will be stressed. The pivotal role of physicians in such a complex process will be highlighted too. The manual will contain several case histories with short descriptions of various aspects of certification practice, examples of most common errors, and examples of correctly completed certificates for each incorrect case. A draft manuscript is to be evaluated by October and its final version is expected by January 2004.

The second product we are about to develop is a Web-based training course to be developed only in English for use with the Internet. It will be used as an e-learning training course on certification. It will contain introductory pages on the importance of good completion practices, details on the aims of the training, examples on natural and external causes, and a tutorial part with interactive completion of death certificates and multiple choice tests. After completion of each exercise, the user will receive an immediate answer about the correctness of his/her answers; a dialog box will be activated if help is needed. The e-learning tool prototypes will be tested during the project; its final release is scheduled for the end of the contract, during Summer 2004.

Lastly, the third product is a basic-information leaflet in two languages (English and French). It is intended as a quick reference guide, pocket-sized, to be used in everyday practice, so it will contain concise, quick information and instruction. It is supposed to be spread in a campaign or intended for widespread dissemination. A first leaflet draft will be evaluated during next November, while its final release is scheduled for the end of the contract, during Summer 2004.

These are more or less the main features of this project. Thank you very much for your attention.

Discussion

PARTICIPANT: I just have a brief question for Dr. Becker. How do you go about getting copies of INTERCOD? Is it available for people who were planning to run courses on coding and so forth? What limitations, legal and otherwise, are there for its use? Thank you.

R. BECKER: INTERCOD is copyrighted by PAHO. To get copies, just send an e-mail to us. We send them by special mail and we ask for $30 to cover the e-mail and part of the cost of production. About the limitations, well, it is a self-instruction package, so it depends very much on the trainee. It is for manual coding, not for automatic coding.

PARTICIPANT: I have a question for Monica Pace about the certification product. In Canada, we are at the very first stages of putting one together. Because we are a statistical agency and not a registrar or a legal advisory in that sense, we at Statistics Canada find it very difficult to promote the certification when we are not legally responsible for what the physician puts on the form. Medical associations and their malpractice legal issues around it take priority over the statistical need that we have at our statistical agency. I was wondering how you were advising your member countries to address that issue? Thanks.

M. PACE: The situation varies. I mean there is not a single situation in Europe, as you can easily understand, from the list of countries involved. Obviously, it is something that we, as statistical institutes, at the level of Eurostat should try to disseminate and to campaign as much as possible asking the assistance of physicians. I think that physicians should be involved in this project. I mean that maybe we can give them credits for their Continuing Medical Education. On principle, we should try to involve all the actors in this by convincing them of the importance of the quality of data.

For instance, in my country, physicians are obliged by law to complete death certificate for statistical purposes. They already know that this is for statistical purposes. So I think it varies from country to country; it is a challenge we will try to accomplish the best way we can.

PARTICIPANT: As you say, there is a wide range in Europe of different legal frameworks; trying to cover all the causes of death and how they should be certified, how will you deal with the question of who is allowed to certify particular kinds of death? For example, in England and Wales, you cannot certify deaths from accidents or violence.

M. PACE: This issue was discussed in the first steering board meeting we had with Lois Fingerhut's (Injury ICE) group participating. One of the first suggestions that we are trying to explore is to keep a warning before the chapter dealing with the standard cause of death in which each country has to pay attention that each physician should or should not complete that part of the training according to the laws in his/her country. This is one of the solutions that Lois suggested to the steering board.

PARTICIPANT: I believe it is not just for external causes. There are countries where doctors cannot complete a certificate for death when no one else is present.

M. PACE: Yes, the material we develop will be sort of generalized; we cannot really take into account each country's requirements. It will be the responsibility of each country to adopt or to select which part of the complete tool is useful for its purpose. So I think you should be flexible and allow each country to use parts that best fit with its own requirements.

PARTICIPANT: Is it actually a self-teaching course they can do or just very short instruction?

M. PACE: The very short instruction is supposed to be the leaflet, the printed reference. Regarding the software, I think it could be considered as self-instruction, but it is intended for use in the classroom, also in the last year of medical school.

PARTICIPANT: I am interested in the teaching package for physicians because there was a lot of information yesterday that was very important for the doctor, but I did not see an interesting, interactive package for them. Most are designed for the coder, not for the physician. I went to the Web site of NCHS, and found a very old handbook of how to write a death certificate and only two pages written for the coroner. Are you going to design an interactive teaching program at NCHS?

T. AMBROSE: At Research Triangle Park, we do not do training of the physicians on filling out the death certificates. Our Hyattsville office has developed some materials, though, for handing out to physicians to give them some guidance on that. I believe it is paper-based.

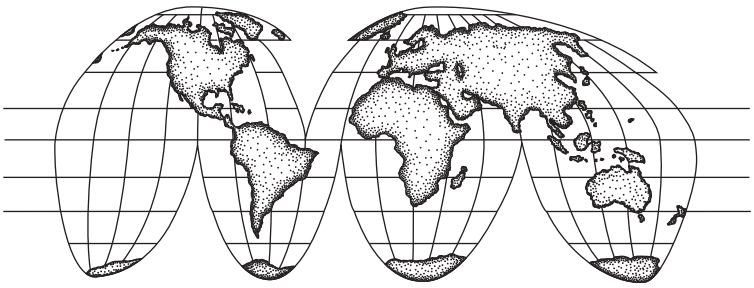
A. MININO: Yes, most of our handbooks are available in hard copy, but they are also available through our Web site. There you can get PDF versions of them. These handbooks are directed to the physicians and to the coroners and to different people who take part in the process of collecting the data.

L.A. JOHANSSON: I have a question for Julia Raynor. You said that multiple-cause coding requires patience and perseverance, and I completely agree. Apparently you have had the same experience as we in Sweden. Could you say anything here about just how many people you lose before they have completed the course?

J. RAYNOR: I am sorry. I do not have statistics on that. We usually get our students from the state vital statistics offices, and sometimes they are not fully aware of what they are getting into. Once they find out how difficult it is and how long it takes, they become very discouraged. I do not have the statistics that you are asking for, but the ones who do stay with it do well.

SESSION 7

Comparability Studies



Session 7: Comparability Studies

Leslie Geran (moderator), Health Statistics Division, Statistics Canada

We will discuss comparability studies in this session. This is a very broad topic, because it is possible to compare anything to anything else throughout the production and dissemination of mortality statistics. For example, one can do a comparability study to assess the impact of a new production process, going from manual to automatic coding. One can do a comparability study to assess the impact of a new classification, moving from ICD–9 to ICD–10. Finally, one can do comparability studies on how the data are gathered, calculated, and published.

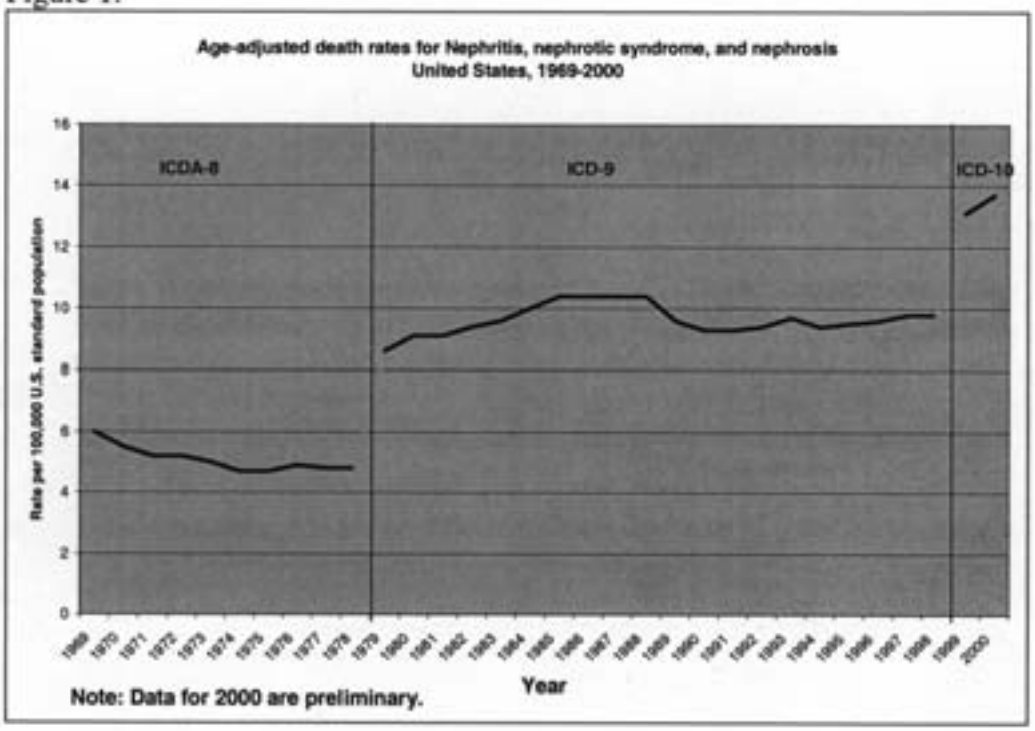
For this session, we are only going to look at comparability studies for a change in classification. Doing comparability studies is a recommended practice identified by the first ICE in 1996. It is topic two, recommendation four. We are going to have four speakers today: Arialdi Minino from the United States, Ron Casey from Australia, myself from Canada, and Cleo Rooney from the U.K.

Measuring Comparability Between ICD–9 and ICD–10 in the United States

Mr. Arialdi Miniño, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

Since I am the first participant to introduce the subject of comparability between the Ninth and Tenth revisions of the ICD, I feel that it would be a good idea to touch briefly on the reasons why we carry out these studies on comparability, and why we believe them to be important. Figure 1 shows the age-adjusted death rate for ''Nephritis, nephrotic syndrome and nephrosis'' in the United States. The rate is plotted across time and across three revisions of the ICD. Those vertical bars represent a change in revision.

Figure 1.

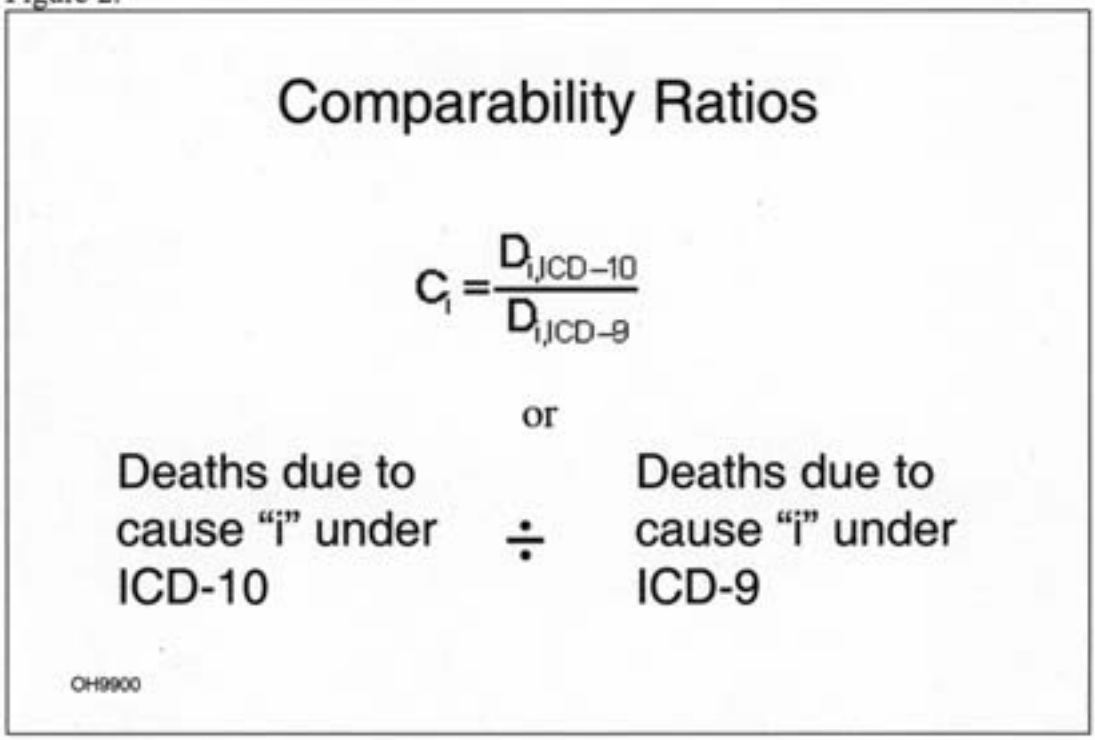


The death rate of this cause appears to remain generally stable within each of the revisions. Of course, when a change in the revision takes place, then we see a dramatic change in the statistics: there is a 79 percent jump between ICD–A8 and ICD–9. Again, it goes up 34 percent between ICD–9 and ICD–10. From a statistical point of view, the challenge is trying to differentiate between the portion of the change that can be attributed to the introduction of the revision of the ICD and that which can be attributed to real changes in mortality risk.

In general, we tackle this problem by taking a large sample of mortality records and then coding these using the rules and criteria of both the old and the new revisions. This we call ''double coding.'' We then compute comparability ratios based on these data. Finally, a clear picture of the effects of change in revision emerges after reviewing what happens to the records classified to a cause of death under one revision and then under the other revision. This is something that we can call the inflow and outflow of these records into a category, that is, what goes in and out of a given category depending on the revision.

The comparability ratio measures the degree of discontinuity between revisions. The ratio for a specific cause is computed by dividing the number of deaths due to that cause when classified according to a later revision by the number of deaths classified to that same cause under the previous revision. Figure 2 shows the definition of an ICD–10 to ICD–9 comparability ratio. A ratio that is less than 1.0 results from fewer deaths being classified to cause ''i'' under ICD–10 compared with the comparable cause under ICD–9. A ratio greater than 1.0 indicates that a larger number of deaths is being classified to cause ''i'' under ICD–10 relative to those classified to a comparable cause in ICD–9.

Figure 2.



The comparability study for the U.S. data was a two-phased project: a preliminary phase that concluded with publication of the National Vital Statistics Report titled, ''Comparability of Causes of Death between ICD–9 and ICD–10,'' and a final phase that we plan to complete in about 3 to 4 months with a final report of our findings. We timed the publication of our preliminary estimates with the publication of our mortality data for 1999, which was the first year that used the Tenth Revision of the ICD. Our preliminary estimates of comparability ratios were based on a large non-random sample of mortality records from our 1996 file. Most of the 20 percent excluded records were rejected, that is, they were not processed by the automated coding system. About three percent of these rejected records were manually coded and included in the sample in time for the release of the preliminary report. The preliminary comparability ratios were limited to the list of 113

selected causes and to the 130 selected causes of infant death, which we usually report without disaggregating by sex or other variables. Along with the preliminary report, we published a guide on statistical methods for the application of comparability ratios to data.

Some of the features and improvements that the final report will have relative to the preliminary report are the following:

- All or nearly all of the rejected records excluded from the preliminary sample have been manually coded and included in the final comparability file.
- Multiple causes for the ICD–10 portion of the file have been included and will allow for multiple-cause analysis across revisions. Thus, the totality of the 1996 mortality file has been completely double coded.
- We want to be able to release the final comparability file as a public-use CD-ROM, so that researchers, officials, and academics might be able to produce results suitable to their particular needs.

Data processing of the ICD–10 portion of the file was completed by late December last year. We are now in the process of reviewing the data to ensure that it is free of errors.

Our plans for analyzing the final comparability file include preparing final comparability ratios for NCHS's standard mortality tabulation lists, including the lists of 358, 113, and 39 selected causes, plus the list of 130 selected causes of infant death. We would also like to analyze a list of external causes that are classified by both mechanism and intent of injury in the so-called ''injury matrix.'' We also plan to compare final comparability ratios against our preliminary results. We shall assess variability of ratios across age, race, state and sex, and we shall publish disaggregated comparability ratios if we believe that they differ substantially across these variables. For many causes of death, it is imperative that we analyze in detail the inflows and outflows of codes and conditions to and from the given category as the ICD revision changes. When this analysis is done, with the help of nosologists, we can gain very valuable insight into how the rule changes and the classification changes affect comparability. Finally, and I might add optimistically, we also wish to evaluate the comparability of nature-of-injury codes, and possibly other multiple-cause data.

I tip my hat to all the folks that have worked so hard on this project, especially the coders in Research Triangle Park. This file took very long to produce and represents a lot of work by a lot of people. It is also a reflection of the challenges that our decentralized system imposes on our agency as we try to collect data from all the states and reporting areas.

I wish to end my presentation by listing comparability issues in the United States that we consider important. Not all of them deal with causes of death or coding for causes of death, but they are nonetheless important. We are primarily concerned that future changes to ICD will not require the huge overhauls that we have previously seen when one revision replaces another. Rather, we are told that smaller, measured changes will be introduced within the same revision. We are going to be ready to evaluate the impact of these changes using adequate methods and analyses.

Also, there are other issues related to changes in our standards of data collection, including changes to the standard population used for age adjusting in the U.S., changes to the standards of the certificate of death, and changes to the guidelines for collecting and reporting the race of the decedent in the U.S., whereby the decedent may now be classified to multiple race categories as opposed to a single racial code used previously. All these are very important and interesting issues; however, discussing these at length is the subject of yet another forum.

Thank you very much.

Discussion

E. JOUGLA: Do you use the comparability ratio to correct the data, or is it just an informative ratio?

A. MININO: No. They also have an application aspect to them. They can be used to adjust or modify the preceding data to compensate for the effect of the change in the revision, so that if you wish to have a trend that flows backward into time, you may see what the rate and the numbers may have looked like had they been coded by ICD–10. That is another use of these ratios.

A.H. SANTO: Ari, you said that the comparability was represented by means of a list of 113 causes. Is it possible to display the comparability by other lists for chapters for categories and so on?

A. MININO: Yes. The idea is that eventually the data will be released on a CD, so that people with skills in data analysis may be able to produce comparability ratios that are suited to their needs and interests.

G. LEGALL: What are some lessons that you learned from this exercise that you can share with countries like ours who want to do coding?

A. MININO: The first lesson is that these studies are very difficult. It has been difficult to keep track of many minutiae, for example, with regards to our input files, to make sure that they are actually the amended files and that they reflect what has actually happened to the decedent. I think that was challenging for the data processors. Other than the complexity, it is something for which you need to think and plan carefully. It is not something that should be undertaken lightly, that is, just taking a whole bunch of records and coding them to see what happens. That, I think, is an observation that may be worthwhile for others planning to engage in this type of enterprise.

L. GERAN: I think some of the other speakers will have more suggestions for you. Ari had raised a point about doing additional comparability studies when the ICD is updated. I am not sure what form that will take and to what degree the classification is going to be changed. It might be helpful if when an update is made, that the people who are doing the update, for example, the Mortality Reference Group (MRG), would be able to give a recommendation about whether a study should be done, or what the impact could be.

C. ROONEY: I agree. Although it is very difficult to tell beforehand what the impact might be, the changes that are recommended by the MRG are classified as being minor or major. One of the factors in deciding whether it is major is whether you think it will have an effect on statistics. So a minor change can be an addition to the term of the Index for a very rare disease that is not there at the moment. That is not going to change your statistics on ischemic heart disease or pneumonia. However, a change to the application of the selection rules is, by definition, major. You cannot say how big the effect will be without doing the study, and you cannot say that a study done in one country will predict what will happen in another country.

A. MININO: I agree with Cleo. One of the things that we found in our study was that the changes to the rules for classifying the underlying cause had a major effect on comparability, much more so than adding codes or removing codes, etc.

Introduction of ACS and ICD–10: The Australian Experience

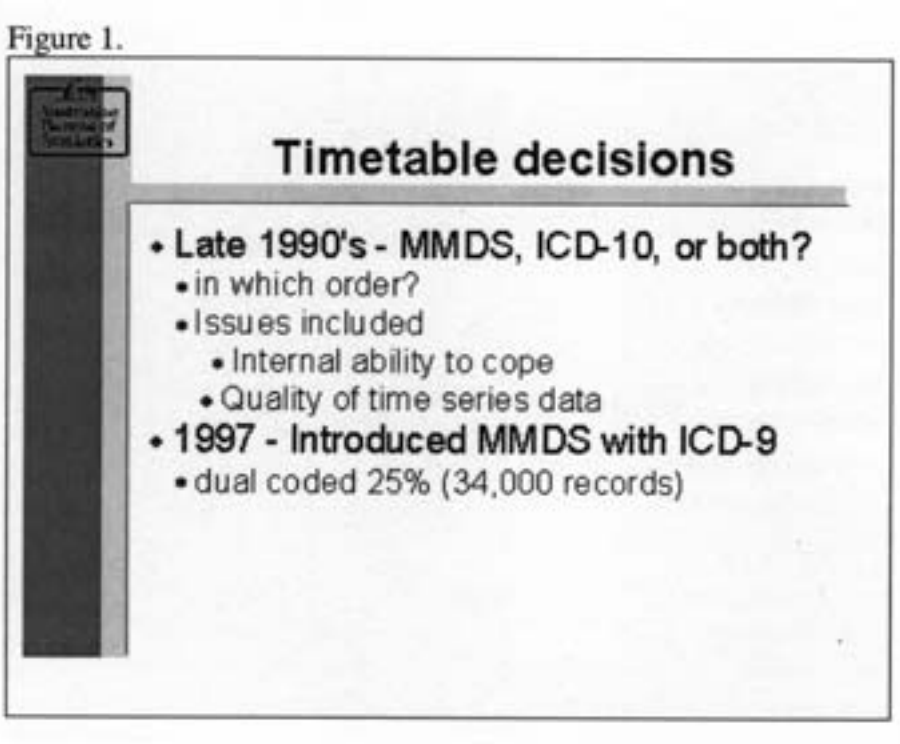
Dr. Ron Casey, Australian Bureau of Statistics (ABS)

Before I start talking about Australia's introduction of ICD–10, I will put a historical perspective on how Australia collects and codes its mortality data to give you an idea of the changes we have undergone in the last 10 years, and how those in turn have affected some of the quality of our mortality data.

Within Australia, all deaths and causes-of-death data are collected by the Registrars in each State and Territory. Prior to 1993, each of these individual State Registrars had their death registrations processed by the regional office of the Australian Bureau of Statistics (ABS). The ABS has regional offices in each state capital of Australia, in addition to our head office in Canberra. This practice had been followed for years under the various versions of the ICD up to 1993, at which time we were coding manually using ICD–9.

In 1993, we centralized cause-of-death coding within the ABS, coding all death registrations in the Queensland office of the ABS in Brisbane. Within that centralized format, coding was done manually using ICD–9 from 1993 to 1996. Late in the 1990's, we needed to make a couple of decisions about where we should go in terms of cause-of-death coding. There were a couple of issues that we needed to look at, one of which was obviously the introduction of ICD–10. At the same time, we became aware of the automated system that NCHS had developed, MMDS, and we wanted to introduce that as well. We therefore needed to make a decision about how we should implement both ICD–10 and MMDS, as shown in Figure 1. Were we going to introduce them together, or if not, in which order were we going to do it?

Figure 1.



Obviously, there were a number of issues that we had to think about in making those decisions, which included our ability to cope with such an upheaval or two upheavals in our processing cycle, and also the quality of our time series. In the end, we decided that we would introduce the automated system first, that we would give ourselves two years for that to bed down, and then we would introduce ICD–10. So we introduced the MMDS system in 1997, or more specifically, for 1997 data; the actual coding did not commence until 1998.

We dual coded 25 percent of the records for that first year, using both manual coding and the automated system. I might just say that we determined that we would do this well beforehand. Although we had decided to introduce the automated system first and then ICD–10, it was always our intention to only have one break in series, and to produce one set of comparability factors between ICD–9 manual and ICD–10 automated, even though we were introducing them in two separate stages.

Then in 1999, the first year for which we coded data using ICD–10, we back-coded the 1997 and 1998 data that we had already coded using the automated ICD–9, using ICD–10. That allowed us to get a direct comparability from ICD–9 manual to ICD–10 automated. So, for that 25 percent sample of 1997 data which I mentioned before, we actually had data coded by ICD–9 manual, ICD–9 automated, and ICD–10 automated. That allowed us to derive direct comparability between ICD–9 manual and ICD–10 automated. We were able to produce from that direct comparability what we called ''concordance files,'' as well as comparability factors. Concordance files are the actual cross-matched coding between individual records coded by both ICD–9 and ICD–10.

Users of Australian mortality data find these concordances quite useful. In fact, I sometimes think we are giving them more information than they actually need. Rather than just using the comparability factors, users want to know for a particular code in ICD–9 how many records went to a particular code in ICD–10, and how many went to another code, etc. Figure 2 gives an example of one of these concordances, that is, showing for a particular ICD–9 code, 290, for which there were 767 observances, how those 767 observances were coded in ICD–10. For those of you who might be already looking at this and saying that a particular code-to-code concordance is impossible between ICD–9 and ICD–10, I might add that this data includes any mistakes that might have been made, either in the ICD–10 coding or the ICD–9 coding, or in the interpretation of codes that might have been made under either coding system.

Figure 2.

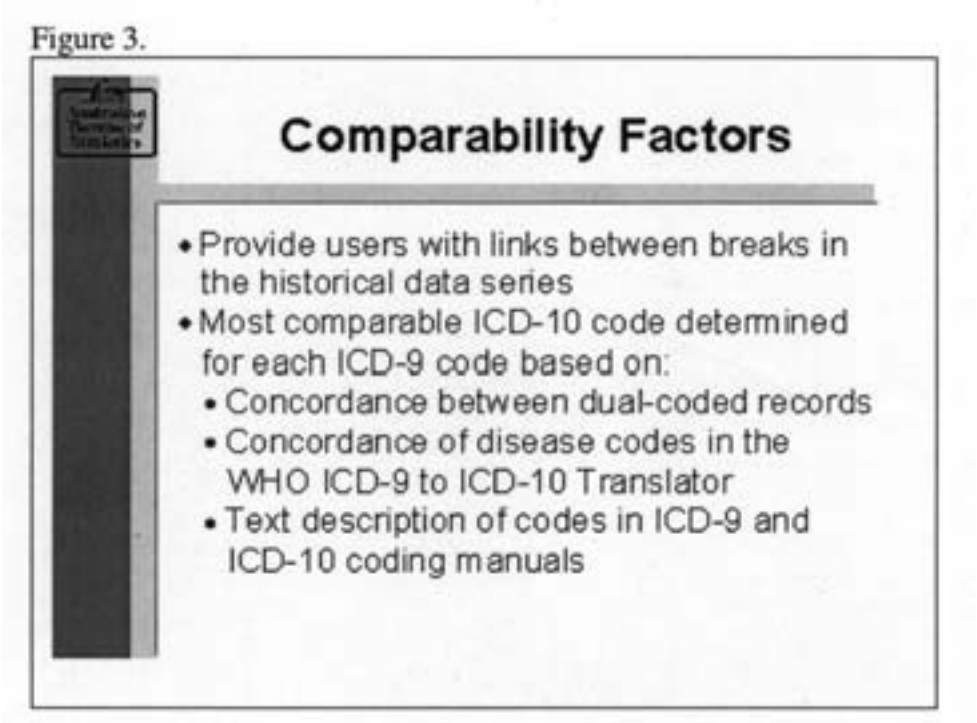
Concordance (example)

Organic, including symptomatic, mental disorders (dementia)
ICD-9 code 290 (n = 767)

Cause	ICD-10 code	Count
Unspecified dementia	F03	479
- other dementia	F01-2,04-10	12
Alzheimer's disease	G30	128
Cerebrovascular diseases	I60-69	27
Atherosclerosis	I70	10
- other Chapter IX	Ixx	25
Urinary disorders (other)	N39	16
External causes	V01-Y98	11
All other causes		59

Figure 3 discusses how we produced our comparability factors, which provide our users with a historical link between breaks in historical data series.

Figure 3.



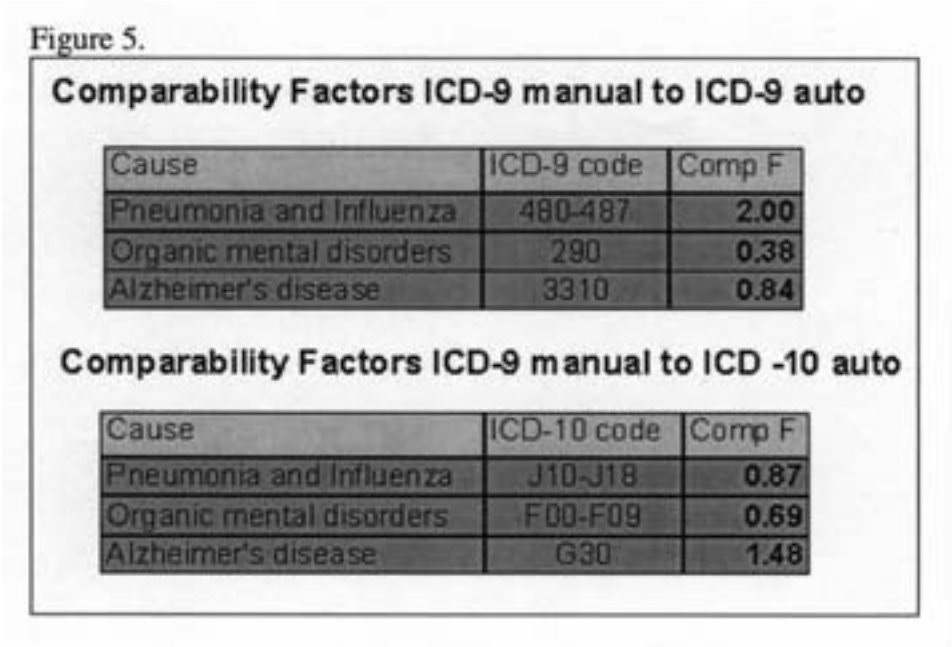
In determining our comparability factors, the major influence obviously was the coded data itself. As we were trying to provide a historical link between our data, we looked at three factors, the major one being the actual concordance between the dual coded records to try to identify what was the most comparable concordance between different causes. We also looked at the concordance of disease codes in the ICD–9 to ICD–10 Translator, and we looked at the text descriptions of the codes in the ICD–9 and ICD–10 coding manuals. The final individual comparability factors were then decided upon based on these three factors, which allowed us to produce a full set of comparability factors, shown in Figure 4.

Figure 4. Comparability factors by selected chapters of ICD-10.

Cause	ICD-10 code	ICD-9 code	Comp Factor
Ch I - Infectious & Parasitic	A00-B99	001-139	1.25
Ch II - Neoplasms	C00-D48	140-239	1.00
Ch III - Blood diseases	D50-D89	279-289	1.07
Ch IV - Endocrine/nutritional diseases	E00-E90	240-278	1.01
Ch V - Mental/behavioural disorders	F00-F99	290-319	0.78
Ch VI - Nervous system diseases	G00-G99	320-359	1.20
Ch IX - Circulatory system diseases	I00-I99	390-459	1.00
Ch X - Respiratory System diseases	J00-J99	460-519	0.69
Ch XI - Digestive System diseases	K00-K93	520-579	1.05
Ch XII - Skin/subcutaneous tissue diseases	L00-L99	680-709	1.06
Ch XIII - Musculoskeletal system diseases	M00-M99	710-739	1.15
Ch XIV - Genitourinary diseases	N00-N99	580-629	1.14
Ch XVI - Conditions orig in perinatal period	P00-P96	760-779	0.96
Ch XVII - Congenital malformations, etc	Q00-Q99	740-759	1.03
Ch XVIII - Symptoms, signs, findings n.e.c	R00-R99	780-799	0.76
Ch XX - External causes	V01-Y98	E800-E999	1.06

Figure 5 shows comparability factors for three causes between ICD–9 manual and ICD–9 automated, as well as between ICD–9 manual and ICD–10 automated. This shows that if we had had two distinct breaks in historical series, and we had produced comparability factors between ICD–9 manual and ICD–9 automated, and then another set of comparability factors between the ICD–9 automated and ICD–10 automated, we would have had some quite large movements for some causes. The major issue was the difference in terms of how Australia was treating pneumonia in ICD–9 manual coding compared with how it was being coded by the MMDS automated system. However, the MMDS system actually changed the way it treated pneumonia in ICD–10 and became more closely aligned with how Australia had treated it coding by ICD–9 manual, so the differences to some extent cancelled out when we made the change to ICD–10.

Figure 5.



Comparability Factors ICD-9 manual to ICD-9 auto

Cause	ICD-9 code	Comp F
Pneumonia and Influenza	480-487	2.00
Organic mental disorders	290	0.38
Alzheimer's disease	3310	0.84

Comparability Factors ICD-9 manual to ICD -10 auto

Cause	ICD-10 code	Comp F
Pneumonia and Influenza	J10-J18	0.87
Organic mental disorders	F00-F09	0.69
Alzheimer's disease	G30	1.48

Some of the issues that we had to address in undertaking the comparability study were as follows. Obviously, a major factor we had to address was staff training. Very quickly, within a couple of years, we had to get our staff trained and familiar with the automated MMDS system, and then very soon after, we needed to have them trained in ICD–10. These are certainly not issues that you should underestimate.

Another issue which I sometimes think people do not fully understand or appreciate before they go into introducing a new version of ICD is just the amount of technical assistance in programming that you need. The programmers need to understand the differences between the different environments in which the coders are working. They need their own separate training. If you are dual coding between two different editions, say ICD–9 and ICD–10, they have to be able to manage the processing overlap between the two editions.

We also had a number of quality issues, especially in relation to the back coding. Trying to do the back coding of 1997 and 1998 data at the same we were coding 1999 data, which was our first year of ICD–10, was obviously an imposition on our permanent coders that was above and beyond that with which they could actually cope. So we enlisted some health information management students through one of our local universities to help us do the back coding. The students did that quite well to varying degrees. Some of them found it difficult to make the transition between learning ICD–9 in an educational-type environment, and actually applying it in a large volume, practical environment; it meant that we required a fair amount of recoding by our permanent staff, which held up the process further than we thought it might.

Everyone says that when you do a comparability study, for example between ICD–9 and 10, you should not have the same person coding the record by ICD–9 and ICD–10 together. Rather, you should code them separately. We followed that maxim by the book, without any reconciliation, except that we made an exception for drug-related deaths and suicides. The only reason we did this was that these causes are highly profiled in Australia; therefore, we wanted to ensure time series in ICD–10 that were as accurate as possible. That meant, when we reconciled deaths from suicide or drug-related deaths, if we found an incorrect ICD–10 code we changed it, although it must be borne in mind that the numbers of deaths from these causes are fairly small.

Finally, just to talk about the lessons that we learned, the first thing is not to underestimate anything, especially the time it takes to get anything done. We were overly ambitious, especially with all the back coding. In hindsight, we were going a bit into the world of the unknown, and we did not know how long or how easily we could incorporate the MMDS automated software. We had decided to take 2 years to implement that before we introduced ICD–10. As it turned out, the MMDS system introduction was fairly seamless and

easy to institute. It is quite easy to make decisions in hindsight, but it would appear that we might have been able to introduce ICD–10 only 1 year after the introduction of the MMDS software, which would have meant that we would have had to back code only 1 year of data.

The other lesson we learned relates to the internal management of the process. We probably could have better deployed our student coders and better utilized the permanent staff in monitoring their progress more closely.

Thanks very much.

Discussion

L. GERAN: Do we need to change the machine again? The problem of just the sheer volume of records that are done in these bridge-coding studies is incredibly hard on the staff, either your permanent staff or any temporary staff you get. In Canada, we do not have any private-sector coding firms that can be brought in to do this coding. I think they did in the United States, though? Bob is nodding yes. How did you monitor the private-sector companies, and was there any difference between how the coding was done by your own coders versus a student coder versus a private sector company?

R. ANDERSON: We have at least one private contractor, maybe two, that we work with for the coding. These are people who have previously worked for us as government employees, and so we know that they are very well-trained. We do some quality control on the firms as well, but generally they do a pretty good job for us. Donna Glen would have more details about the monitoring.

S. NOTZON: I have a question for Ron. Could you tell us which was more difficult, the transition to an automated system or the transition from ICD–9 to ICD–10?

R. CASEY: I think it would have been the transition from ICD–9 to ICD–10. The transition to the automated system was fairly seamless, but we were coding the same sort of information, just using a different system to do it with. On the other hand, for the ICD–9 to ICD–10 revision, we had to familiarize ourselves and get trained in an entirely new set of coding rules and logic. I do not even know if we can confidently say that we did it in the end, but certainly it was more difficult going from ICD–9 to ICD–10.

Canadian Comparability Study Design and Preliminary Results

Leslie Geran, Health Statistics Division, Statistics Canada

My presentation is on the Canadian comparability study of ICD–10 implementation, focusing mostly on the design of the study and providing some preliminary results. The study was a team effort with our methodologist Sylvia Auger, nosologist Patricia Wood, analyst Patricia Tully, and myself. Not listed as authors but not forgotten are the staff members at our operations division, who did final manipulations and recording. Even automated systems need a lot of people, and as Patricia Wood always reminds me, ''automated does not equal automatic.'' They are very different things.

I will tell you a bit about the Canadian vital statistics system because it had a great influence on the comparability study design. We have a population of about 31 million in 10 provinces and 3 territories. Two of the provinces have large French-speaking populations. There are about 220,000 deaths a year. Since the registration of vital events is a provincial and territorial responsibility, the operational and analytical capabilities and interests of the registrar offices vary greatly whether they are registering 81 deaths a year, as is done in our smallest territory, or 81,000 deaths a year as in Ontario, our largest province.

Statistics Canada has a collaborative role in promoting national standards in vital stats, large or small. All jurisdictions use death registration forms that are modeled on a national standard, including the medical certificate of death as recommended by the World Health Organization. Everybody implemented ICD–10 in the year 2000, and it fell to Statistics Canada to do a comparability study, using 1999 data.

Although the registration of deaths is decentralized, the classification of deaths is somewhat centralized because the smaller jurisdictions do not have the volume of deaths to maintain and develop a coder's experience. Three larger provinces do their own mortality classification, using automated systems. Quebec uses STYX, and MMDS is used in the other two. One province does data capturing using PC-MICAR. Now they use SuperMICAR because of the change in the MMDS system, and Statistics Canada does their reject resolution for that province. For the eight other provinces and territories, Statistics Canada does the mortality coding using a mix of automated and manual systems.

In summary, the 3 largest provinces that still do their own coding represent 75 percent of the deaths in Canada in 1 year, and Statistics Canada does coding for the other 25 percent.

When our team first talked about doing a comparability study, we had a lot of concerns about the amount of time it would take and the lack of coding resources we had, especially when one of our senior coders retired. Harry Rosenberg from NCHS visited us in June of 2000 to give a course for the analysts, and at that time he gave us some excellent suggestions on how to do our study, including re-using the ICD–9 data capture from PC-MICAR as an input for MMDS and ICD–10. That made the task of recoding a little less daunting, because we could automate some of it. Because we had those files from the jurisdictions, we did the coding ourselves, and we could get the files from those provinces that do their own automatic coding, or at least, that was the theory at the start.

What really happened is that we had to divide our study into four subsets. Subset one (1) includes the provinces where Statistics Canada does automated coding. We reran the inputs using ICD–9 through MMDS for ICD–10, with a Statistics Canada coder resolving the rejects. We are about 88 percent complete on that now. Our goal is to have 100 percent of the records coded in subset one in both ICD–9 and ICD–10, and that represents 14 percent of the total deaths in 1999.

We still do some manual coding. We did manual coding ICD–9 for the northern territories, so we did ICD–10 coding manually as well. The goal was to have 100 percent of subset 2 (2) coded in the two revisions. We finished this, which was good, but unfortunately this represents less than 1 percent of the total deaths in 1999.

Subset three (3) includes the provinces that did their own automated coding using MMDS. We got the files from those provinces and reran the inputs in ICD–9 through MMDS for ICD–10. Statistics Canada resolves the rejects, which is still ongoing. The goal is to have 100 percent of these records in subset 3 coded to the 2 revisions, which represents 54 percent of the total deaths in 1999.

In subset four (4), we are unable to get MMDS inputs from these provinces, either because they did not exist as in the provinces that had substantial French-speaking populations, or because they deleted the files and did not have them any longer. Our goal is to have 10 percent of the records in subset 4 coded in the 2 revisions. This represents 32 percent of our total deaths in 1999, so this is our sample subset.

In summary, about two-thirds of the 1999 deaths were in census subsets, where we are going to double-code every record, and one-third were in the sample subset, where we are going to code 10 percent.

First of all, in planning how to select the sample, we did not have our 1999 data available at the time when we started planning the study, so we used our 1997 file, reasoning that the causes of death did not change much from year to year. Thus, we used the 1997 file for planning how to select our sample. We figured we had the time and the money to recode about 7,000 records, or 10 percent of the 70,000 records in subset 4. We did not want to use simple random sampling to pick the sample, because we figured if we threw everything into a hat and then started to draw them out, it was likely we would have a lot of heart disease and malignant neoplasms, and not necessarily all the other causes of death that would have been affected by changing revisions. Therefore, to find all those other causes, we put our methodologist to work.

We tried to sample as many different ICD–9 codes as possible. We defined our deaths in two groups or strata. One stratum was for ''rare'' causes of death, that is, for which there were 10 or fewer (including zero) deaths in Canada in 1997. We sampled all of the ''rare'' causes when the 1999 file was available. The second stratum was for ''non-rare'' records, defined as all ICD–9 codes with over ten deaths in Canada in 1997. For these, we sampled at least two records for each of these ICD–9 codes. Using these 2 criteria gave us a sample of 777 records, but we could afford to sample 7,000 records, so how did we select the remaining 6,300 records? Again, we rejected throwing everything into a hat by using simple random sampling. We also rejected another sampling method called proportional allocation because that would really have the same effect. Most of the records in the extra sample would be in the circulatory and neoplasm chapters. So instead, we tried to reduce the variation in the sample by targeting the selection by keeping the sample weight less than 200, which means that any 1 record would represent no more than 200 other records. We tried to control the coefficient of variation. When all is said and done, our total sample was 7,073 deaths in 1,513 different ICD–9 codes, of which we have completed about 2,100 for the preliminary sample.

Calculating the comparability ratios is no different from any of the other comparability ratios you have heard about today. The only difference for our study is that the number of deaths is a weighted number, using a sample weight for the record. Also, the calculation of a standard error associated with the comparability ratio is considerably more complex than for a simple random sample. Based on the coding we have done to date, we have calculated some ratios: for acute myocardial infarction, defined as code 410 in ICD–9 and I–21 to I–22 in ICD–10, the ratio is 0.97; this ratio is relatively close to the U.S. preliminary ratio of 0.99. For the major cause of death in Canada, lung cancer, our preliminary ratio is 0.98, about the same as in the U.S. preliminary study.

We expected a low comparability ratio for pneumonia because of the change in Rule Three about the selection of pneumonia. We have a preliminary issue of about 0.53, while the U.S. had a ratio of almost 0.70. Here we might have a difference in the reported number of pneumonia deaths on the certificate compared with the American certifiers. Because, we have an older population than the U.S., perhaps more of our pneumonia deaths have other conditions on the certificate. For Scotland, the comparability ratio for pneumonia is 0.54, so you can have variability in comparability ratios across countries. We may also have some systems incompatibility. Some of our records may have been processed using earlier versions of MMDS that did not have an update for Rule Three; therefore, we will need to verify this, which may change our ratio as well.

Another leading cause of death is cerebrovascular diseases, for which we have a ratio of about 1.07 compared with 1.06 in the U.S. This example brings us back to the definition of the ratio, the number of ICD–10 deaths for cause divided by the number of ICD–9 deaths for a comparable cause. But what is a comparable cause? For years in Canada we defined cerebrovascular diseases as codes 430–438, but transient ischemic attacks are now in a different chapter in ICD–10. So what is the ICD–9 code range that should be

used in the comparability ratio? Based on the reading I have done in the international studies, some countries include it and some do not. I think we are going to calculate it both ways—making it transparent what was done—and let our users decide.

We still have quite a bit of work to do on our study. We have to finish the reject resolution in the census subsets, especially in Ontario, where they were only able to give us 36,000 of their 81,000 records. We might convert Ontario to a sample province. We still have not decided what to do about this. We will have to complete our sample subset, and we will continue with a quality assessment of the coding. We are a little below 1.0 for the ratio for intentional self-harm. Since suicide is well studied, we want to look at that in more detail. There are certain causes of death to which one should pay more attention, and suicide is definitely one. Then because Quebec uses STYX, we would like to do some sort of comparison between the results we get in MMDS and those we get in STYX, but we have not quite figured out how to do this yet. Future work includes a paper describing this, which will be included in our cause-of-death publications in about a month.

Overall, I have been very pleased with the results we have so far and the methods we have used. If I had to plan to do it again, I think I would use a sample for all the jurisdictions.

Discussion

E. JOUGLA: This is a question for all the authors that have done this type of exercise. You could have a comparability ratio of 1.0, for instance, but it could be a different case. What have you developed as indicators to try to assess the comparability at the individual level? Do you see what I mean?

R. CASEY: I suppose in our case, that is why we had those one-to-one match records, or concordances, as I was calling them. So in a concordance, we can actually say for a particular code in ICD–9, for example, that it has the same code when we went to the ICD–10 code; and also in reverse, we can say for a particular ICD–10 code that it came from the same ICD–9 code. The record comparability could average out with have a comparability factor of 1.00, but it might mean that 70 percent came from one code and 30 percent came from another code, or that 30 percent went to one code and 70 percent went to another code.

L. GERAN: I think we are not going to do that type of presentation because most of our users are looking at time series and are not interested in the details; they will just want to know if they are following the trend in lung cancer deaths, whether the trend goes up or down. We will explain in our notes that these shifts can be made either into or out of a particular chapter or group within it. For special studies, we will work with the analysts on a case-by-case basis to explain it to them.

C. ROONEY: We had looked at the flow of records up to a certain extent, and we have done tables showing cross tabulations of where things moved from and to. I think that Leslie [Geran] is right, that most people using the data are just trying to track progress towards targets in reducing ischemic heart disease, for example; they are relatively happy with that single measure. However, certainly some academics want much more detail, which they will be able to get in our case from making the data available.

One of the issues for which we do not know the answer is whether the deaths that are selected into the group in ICD–10 are a different subset of the total population of deaths that could have been selected into it from those that were in ICD–9, and whether the actual time trend will change. If you are selecting different deaths, are they actually a cause that was going down when the one you were looking at was going up? I do not think we will actually know the answer to that for several years; we will just have to watch and wait, but it will be interesting.

Results of the ICD–10 Bridge-Coding Study: England and Wales

Dr. Cleone Rooney, Office of National Statistics, England and Wales

Like everyone else, I should say that I certainly did not do this study on my own. My co-authors made the presentation about registration in ONS, and Claire Griffiths did a lot of the analysis for us. Also, the coders and the programmers did a huge amount of work to make this work, without which the study could not have been done.

Our methods are very similar to those that everybody else used; the principles are the same. We have the original text from the death certificates stored electronically, so we just put the same text through the ICD–10 system as was put through the ICD–9 system. You try as hard as you can to have both versions coded independently and coded the way your routine data will be coded. However, this was the first time that our coders had coded ICD–10, so even though they had been through training, clearly there is a learning curve, and how they code will change a bit over that period. Also, there is a learning curve for the software because each year people discover bugs in it, which have to be corrected, quite apart from the actual updates. So the software does change a little bit over time. We thought we were using the version that incorporated the up-to-date interpretation of Rule Three, which had been changed by the Mortality Reference Group, with a lot of detail about which diseases should be selected instead of pneumonias, but it now turns out that may not have been quite the final version.

We have prepared three publications, and there are electronic tables up on the Web. We did actually look at rates and ratios by age and sex. Figure 1 shows mortality rates from stroke in men in 1999, which was our comparability year, in both ICD–9 and ICD–10. As Canada found, death from strokes went up in ICD–10.

In addition, the ratio varies by age. In fact, for the more common causes like stroke, I can put confidence intervals on the ratios and show that the over-80's are significantly different from the under-60's. However, with some sensitivity analyses in which we applied age-specific comparability factors to our data compared with single all-age comparability factors, we found that for most of the time trends, it makes no difference. If you are looking at all ages of death, 70 to 75 percent of deaths, for us anyway, are in the over-65's. So the fact that the ratio is lower in the low age groups just does not affect your overall age-standardized rates, which makes it easier for people using the comparability ratios.

Note that if people are specifically looking at a young age group, then I think they have to use the age-specific rates, even though the numbers of deaths are very small. Consequently, the confidence limits on the comparability ratio for the 40–60 age group are huge. Again, people can do sensitivity analyses and decide whether to use the all-age comparability ratio.

We also found that the comparability ratios differ by sex, so we do recommend using a male ratio and a female ratio for the diseases that changed much.

Figure 2 shows data for ischemic heart disease. The lines for ICD–9 and ICD–10 are exactly superimposed. There was virtually no change whatsoever in the number of deaths assigned to ischemic heart disease as a group. You can see that the ratio which is shown on this axis is virtually 1.0 at all ages, which is the same as found in other countries. Death from ischemic heart disease really did not change.

Figure 1.

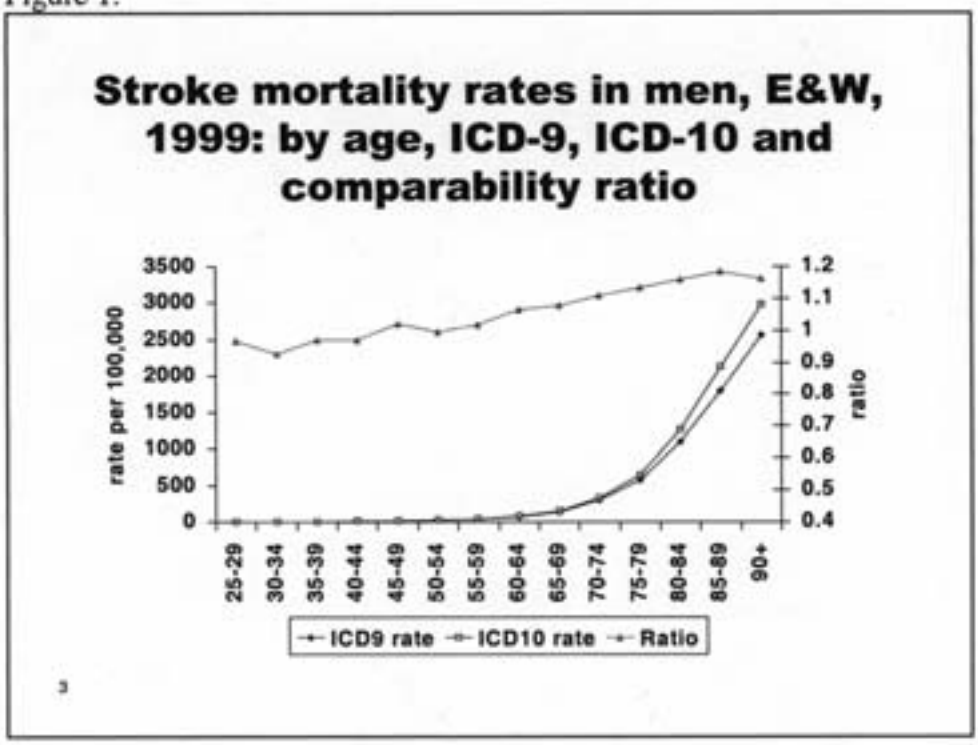
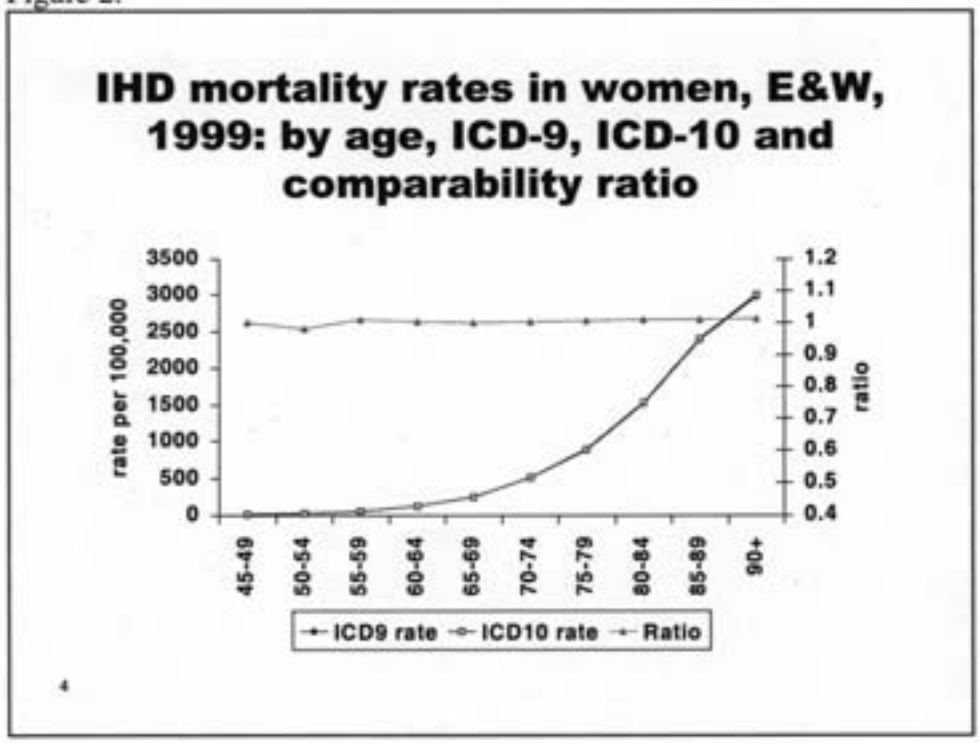


Figure 2.



However, we did find that there were shifts within the group of ischemic heart disease. Acute myocardial infarction went down a few percentage points, an appreciable number of points. Two things shifted out of acute myocardial infarction (AMI). One was myocardial infarction with a stated duration greater than 4 weeks, which becomes chronic, even though it says acute myocardial infarction. The other is other forms of acute ischemic heart disease, which did not have a code in ICD–9. If it was acute in ICD–9, it went to AMI, and now they have a separate code. We also found one odd thing, which is that while almost all countries got a ratio of virtually 1.0 for ischemic heart disease, when the U.S. looked at it in a bit more detail, they had to include in their ischemic heart disease a code from ICD–9 (which I think was 429.8), which is atherosclerotic heart disease. Without that, the U.S. would have had a fall of about 10 percent in deaths from ischemic heart disease. For Scotland and England and Wales, we did not have to do that because we never use that phrase, therefore, we never use that code.

Figure 3.

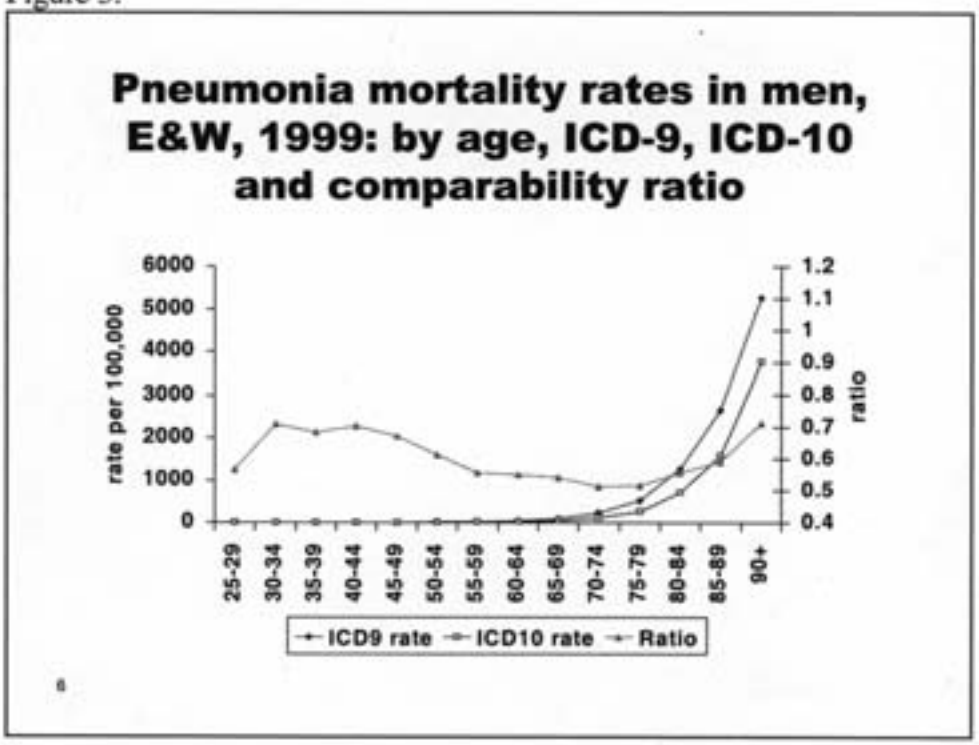
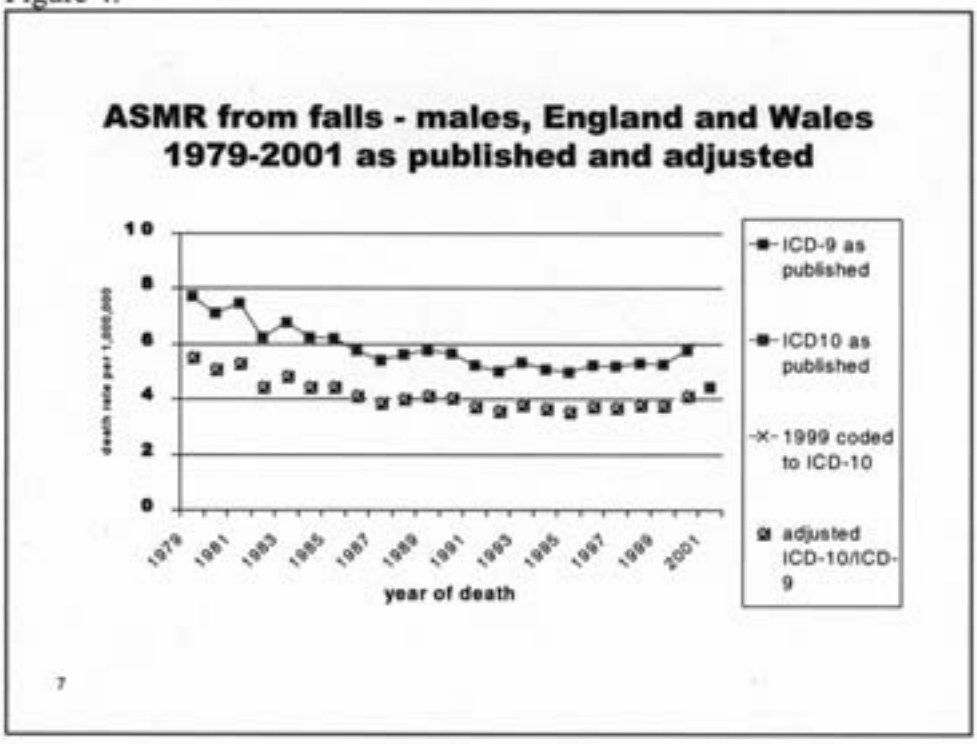


Figure 3 shows the data for pneumonia. After looking at what happened with stroke, I had expected naively that since the comparability ratios go up with age, pneumonia would be the opposite, that is, more deaths that were coded to pneumonia would be coded to something else at higher ages. This is not true; the ratio bounces all over the place, with the peak being possibly related to AIDS and HIV. The first thing to say about the ratio, though, is that it is well below 1.0. We examined that in more detail. In the very elderly, a lot of the certificates do not have anything else written on them, so if there is nothing else you can choose, you cannot apply any coding rules. If the certificate just says bronchial pneumonia, that is all to which you can code the death.

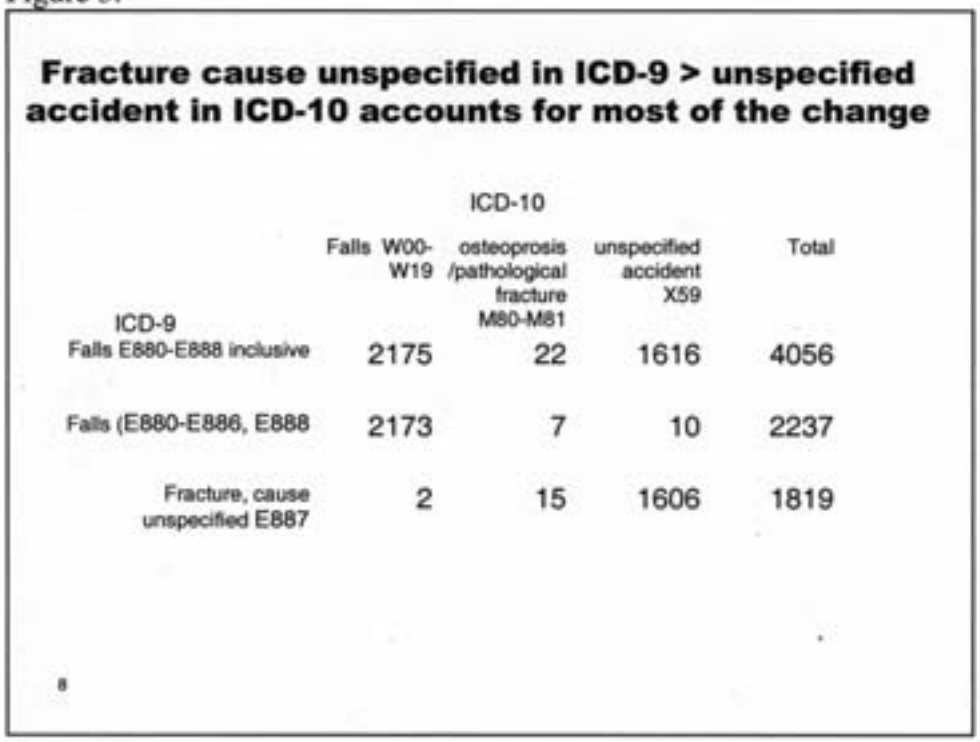
Figure 4.



Death from falls in the elderly is a government target in the U.K., in particular, reducing these deaths by 20 percent. Health authorities have targets they are supposed to meet, and interventions they are supposed to implement. Figure 4 shows the death rate from falls and fractures from 1979 to 2001. The rate initially declined, then flattened out, then started to increase a bit. We looked at the 1999 rate in ICD–10, and it was obviously much lower than the ICD–9 rate. So, this is what you do when you apply the comparability ratio directly to the past data; you just multiply it all by the ratio, and you get a trend that looks remarkably similar because it has all been multiplied by the same ratio, but is lower. You can see that, actually, deaths from falls in the elderly are probably going up a bit at the moment.

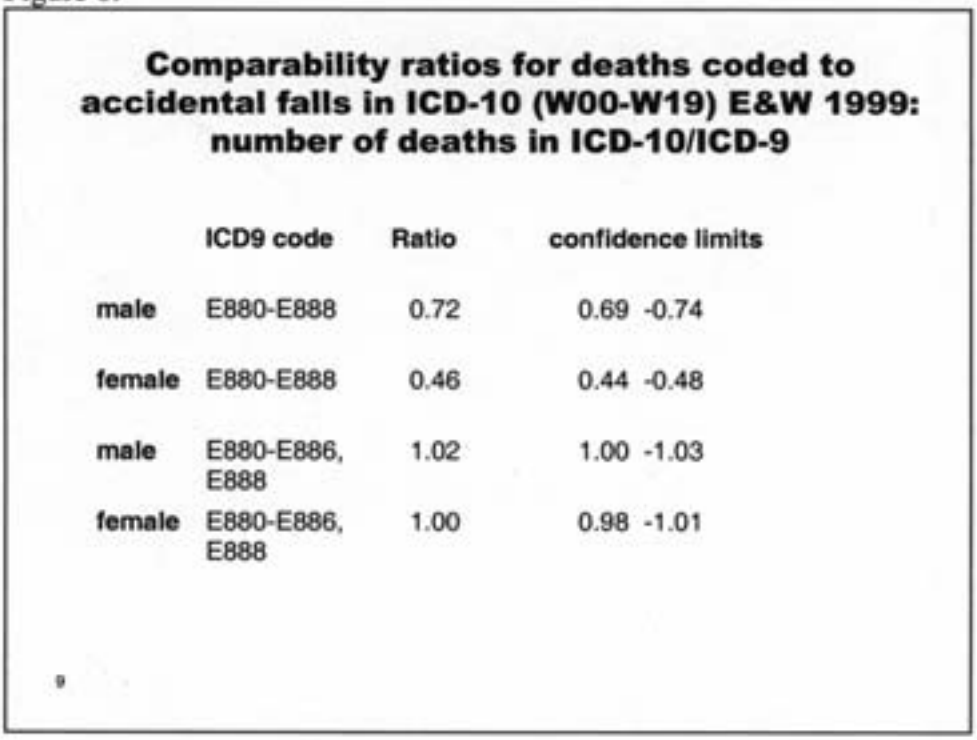
Several things happened between ICD–9 and ICD–10 that could have affected the number of deaths due to falls. In England and Wales, the traditional grouping is E–880 to E–888 in ICD–9, which includes the code E-887, ''fracture, cause unspecified.'' Virtually all of the difference in the total assigned in ICD–9 and the total assigned in ICD–10 was due to deaths in E–887 (see Figure 5). In ICD–10, they all go to X–59, which is ''exposure to unspecified accident,'' a completely useless code. There is no way one can plan an intervention to prevent exposures to unspecified factors. This is one of the areas where, as somebody was saying the other day, ''the perfect is the enemy of the good.'' The injury epidemiologists all said, ''We need more detail than this; one cannot possibly include things like 'unspecified' and just pretend it is a fall. It is no good to dump it here.'' One just does not get on routine death certificates the level of detail that is required for some of the injury and external cause codes in ICD–10. We discussed this in the Mortality Reference Group, and a solution was proposed; the X–59 gets split into X–59 subcategory that will be ''fracture due to exposure to unspecified factor,'' and a subcategory that is the rest of X–59. So we may be able to improve this a bit.

Figure 5.



We can also improve it a bit by using the unknown injury codes. Figure 6 shows that we can use the comparability ratios to adjust the deaths due to falls. There is almost a 30 percent drop among men, and more than half the falls in women disappear. However, if we use the group without the E–887, we get a ratio that is pretty close to 1.0. If you want to look at time trends, you can actually do either in our data.

Figure 6.

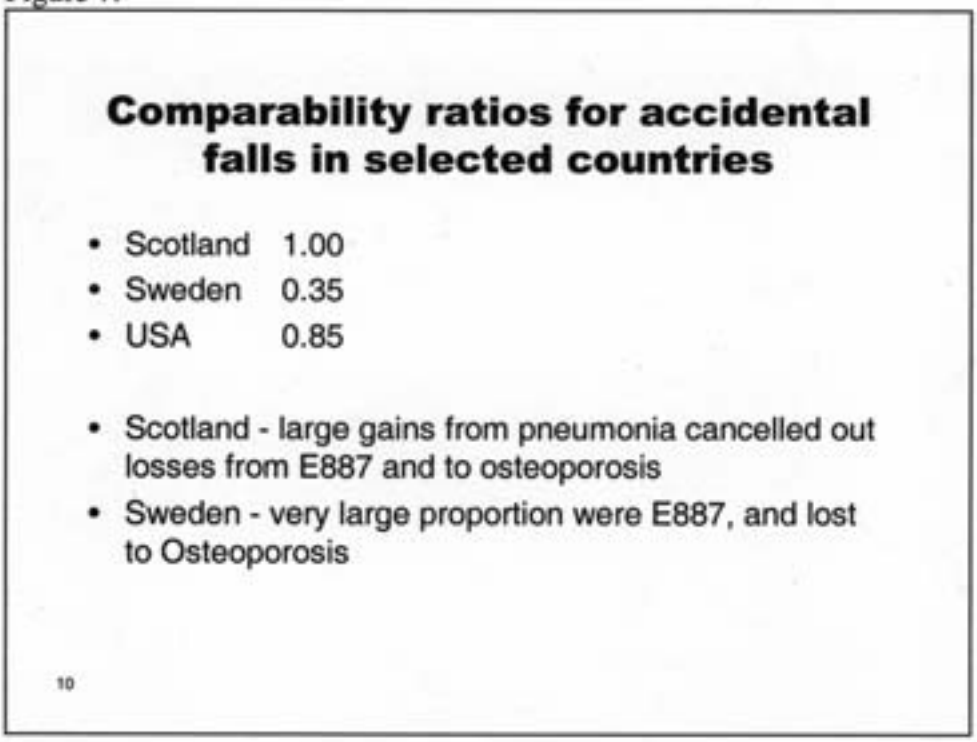


Comparability ratios for deaths coded to accidental falls in ICD-10 (W00-W19) E&W 1999: number of deaths in ICD-10/ICD-9

	ICD9 code	Ratio	confidence limits
male	E880-E888	0.72	0.69 -0.74
female	E880-E888	0.46	0.44 -0.48
male	E880-E886, E888	1.02	1.00 -1.03
female	E880-E886, E888	1.00	0.98 -1.01

9

Figure 7.



Comparability ratios for accidental falls in selected countries

- Scotland 1.00
- Sweden 0.35
- USA 0.85

- Scotland - large gains from pneumonia cancelled out losses from E887 and to osteoporosis
- Sweden - very large proportion were E887, and lost to Osteoporosis

10

In Figure 7, I compared this to what happened in other countries. First of all, data that Lars Johansson gave me from Sweden showed a huge drop. As I remember, most of that goes to the X–59 and a little bit to the osteoporosis. In the U.S., the fall was much smaller. In Scotland, the ratio is 1.0, but that actually hides the fact that almost half of all the falls moved out and another lot moved in. Almost half of the total falls were lost to osteoporosis and to X–59, but they gained as much from the prime Rule Three to pneumonia deaths. Therefore, they ended up with net change of zero.

We are doing some more detailed work by cause. Most of our results have already been published and are available on the Web; however, we have not completed the more detailed work on cancers by site or on land transport accidents, sorting out the specific groupings that people wanted in ICD–9 and ICD–10 and earlier. We are doing some work on main injury because we are one of the countries that publish external cause and main injury for deaths from accidents and violence.

Also, we have coded a sample from 1996 but have not yet analyzed it. We plan to examine the effects of certification drift. What doctors write on certificates changes over time—both the terms that they use and the likelihood that they will or will not include extra conditions. We wanted to see if we could measure that and estimate how far back we could apply the ratios without them becoming nonsense. The data are available to anybody who wants to analyze them.

One issue of concern is how often we are going to have to do bridge-coding studies. The ICD–9 to ICD–10 comparability study was huge, taking years of work, utilizing an enormous number of people, and using a staggering amount of money. We may not be able to do it again next year if the coding rules change again. The agreement on updates is that we should only have major updates once every 3 or 5 years. Sorry, cannot afford it. As I said, I am not actually sure that the Rule Three that we were using and did all this immensely detailed analysis on was quite exactly the one that we will be using for the next few years, so we may have to do additional work on this.

Discussion

R. ANDERSON: Two comments: the first of these is dealing with using the ICD–9 input data to put into ICD–10 to recode using the ICD–10 automated systems. One of the problems that we had was dealing with records that had been amended, that had been initially submitted pending investigation, and then corrected in the final file, but never corrected in the original input files. Therefore, when we originally put together our preliminary results, we ended up with— particularly with the external causes—some fairly low comparability ratios. This was mostly because the ICD–10 data in some instances went to R99 or to another external cause; homicide in one case and then suicide in another, for example. We found that we had to go back to find the amendments where possible, and then plug in the amended information. In some cases, we were not able to locate the amended information, so we have had to actually delete those records from our study.

L. GERAN: We did that as well. We found all these unknowns. I think the problem is somewhat compounded because the records and the amendments are resident in the province; they do not necessarily send along the amendments to us. When Statistics Canada coders were doing the reject resolution for the ICD–10, we just did not have that information, so some deaths went to R99 when they really were from suicide. That is why we think our suicide comparability ratio is under 1.0 and not valid.

R. ANDERSON: At the moment that is part of the effort with which Ari Minino and I are dealing, that is, sorting through the final data to determine which of these have been updated and which have not.

The other comment I had was about what Cleo [Rooney] called the certificate drift, which I think is a very important issue. We noticed that in a fortuitous manner. When we were dealing with the comparability ratio for HIV, the state of Florida was doing its own comparability study. NCHS was dealing with 1996 data while Florida was using 1999 data. They were actually recoding ICD–10 data to ICD–9. They found a substantially higher comparability ratio for HIV disease, around 1.15 compared with ours of 1.06.

Of course, we became very concerned about this and investigated it. We realized that over time, the nature of the certification had been changing, I think, in response to drug treatments. Whereas previously we were seeing HIV listed with what you would consider typically HIV-related conditions—pneumonias and neoplasms and things like that—in the later years, 1998 in particular, this changed over time. There was an increase for 1997, 1998, and 1999 in the presence of unspecified pneumonias and unspecified neoplasms or other neoplasms that were not typically related to HIV. Since we had this rule change that allowed any neoplasm in ICD–10 to be due to HIV, and the change in Rule Three with regard to pneumonia, we saw a fairly large increase in the number of HIV cases. Thus, that ratio was actually increasing over time.

We saw a similar issue with Alzheimer's disease as well because of the increasing certification of Alzheimer's-type dementia, which in ICD–10 is classified to Alzheimer's, but which in ICD–9 was classified to code 290.1.

PARTICIPANT: I think that highlights the importance of planning your bridge-coding study as close to your implementation data as possible, to minimize the certification drift between the study and when you will apply the result.

R. ANDERSON: Yes. It also, I think, highlights the danger of applying a comparability ratio backwards in time without any sort of detailed analysis. You could theoretically apply your comparability ratio all the way back to 1979 at the beginning of the study, but I think that what we are finding is that this is not really advisable. You should probably not do that, at least not much further beyond where you started with your double coding.

R. CASEY: If I could just make a comment there, I think that—as Cleo Rooney was mentioning at the end of her address—you can be bringing in a comparability study for all manner of factors. I talked about how we went from a decentralized system of coding cause of death within the ABS to a centralized system that

brought about an increased quality in the data. We could have actually gone and done a comparability study for that, although it would have highlighted the inconsistencies or the inaccuracies of the coding practice beforehand.

R. BECKER: A brief comment on fractures, and then a question. I remember we discussed both in the Mortality Forum and in Forum C about code X59, where the fractures are now. Some countries maintain their ratio closer to 1.0 simply by coding falls according to the age, for example, over 60 years of age. One example is Cuba. They are not coding unspecified fracture with ICD–10 in X59.

C. ROONEY: So people over 60 cannot have motor vehicle accidents? Be hit by cars?

R. BECKER: I do not necessarily agree, but I am saying that this is happening in some countries. The other thing is related to pneumonias with ICD–9 and ICD–10. As I understood, now you have some 30 percent fewer pneumonias. In a bridge-coding study that Ruy [Laurenti] did in Brazil some 5 years ago, it declined by some 40 percent. Now, all of these are ''in vitro'' studies. The question is who has compared real data? I remember, comparing Brazilian statistics on pneumonia, the published statistics, 1995 ICD–9 and 1996 ICD–10; the ratio was 1.0, practically. Of course, if you are selecting underlying cause by software, probably the ratio is as you show, but with manual coding, who knows? This is the question.

C. ROONEY: I cannot answer whether it is very different when you do manual coding. We have published the trends across this change and across an earlier change in Rule Three that was made only by England and Wales in 1984 and then reversed when we went to manual coding in 1993. George Water made a coding in 1993. Yes, with the real data the pneumonias are going along, they go down then up, and then they level off before going down again. The real data does show it absolutely, and you cannot make sense of it without the ratios. If you change the coding rules, the results change dramatically.

R. BECKER: What it seems like is that the codes are changing, the rules are changing, but not the mind of the coders, at least not immediately.

C. ROONEY: I think that is true; I think that is another reason why the ratios do not apply for a long period on either side. They apply around the years when the change was made. The coders' minds and their practice may change more gradually. However, there are things that can be done to try and minimize that. Certainly one of the recommendations is that you should not have the same coders doing the two kinds of coding, because you just cannot keep two completely different set of rules in your head at the same time. What we did with this was get the new coders to do the bridge coding first and the experienced ICD–9 coders came in later. Once they changed over to ICD–10, they no longer did any ICD–9 coding at all, and they had a period of a couple of months when they were only training in ICD–10, not doing ICD–9, before they changed over to ICD–10 coding.

R. BECKER: The problem is that if you are coding manually you cannot do this; you need the same coder.

C. ROONEY: We did it in ICD–8 to ICD–9, and we did it in 1984.

S. BAH: I have two questions and one comment. I am a bit worried about this practice of combining censal data, the full data and the sample. It looks like in Statistics Canada it is an established practice. I remember reading an article co-authored by Patricia Wood about multiple causes of death, and the same practice was there. It is like some census and some sample. Now, even if some territories submit the full returns, as long as some others submit partial returns, then you would rather take a probability sample of the full returns for the sake of consistency. Also, you mentioned about trying to ensure that some ICD–9 codes were contained in the sample. If there is randomness in the ordering of the returns, then somehow you still get the codes represented if you do a probability sample.

L. GERAN: But we targeted the sample to get as many ICD–9 codes as possible, and then we had a bit of randomness at the end, where we tried to—it was the 6,300 other ones that were more random than the targeted sample. So I think we covered both our bases by that.

S. BAH: The second question is about these comparability ratios. From what has been reported, it looks like the cost involved and the time involved is very prohibitive. So should it be considered having standard comparability ratios that can pull together data from different countries, even though we know there are some specific factors in different countries. In that case, though not all countries can do comparability studies, those standardized ratios can be applied to other countries.

The third comment is on Australia. I think what you did is a good exercise from ICD–9 manual to ICD–10, and then from auto to manual. I believe someone else has tried it, but if someone wants to compare the trend from ICD–9 to auto, then they can just multiply the two issues.

R. CASEY: Well, we purposely went out of our way to ensure that we did not produce two ratios. That is why for that sample in our 1997 file, we coded by ICD–9 manual, ICD–9 auto and ICD–10 auto, so that we could produce just one comparability factor between ICD–9 manual and ICD–9 auto, even though in practice we actually produce the automatic system for 2 years under ICD–9 and then went to ICD–10. From a historic perspective, that is all now seamless. All people now, when looking at historical data, they just see one break, which is basically a break between ICD–9 on a manual system and ICD–10 on an automatic system.

G. PAVILLON: Eric [Jougla] was just saying to me that I should talk about a project I am currently working on, which is an international effort at bridge coding. The idea is, I think, a necessary one: to collect all the bridge-coding studies and make them available in some way for all the countries.

L. GERAN: You actually wanted to collect the data though, did you not? In Canada we are limited by confidentiality, permission, and other rules and regulations in addition to what the provinces will allow us to do. However, I think we would like to publish our study design and results. Our study design shows that there is a way to not have to do all the records, but target some of the records to hopefully reduce some of the costs associated with doing the bridge coding. I think we could use perhaps the Internet bulletin board to highlight some of these studies. Just so you are listening out there, how many countries have done a bridge-coding study? I know Sweden and South Africa have. We have lots, and we should have a place where people can find out about them. Certainly if you are not going to do a bridge coding study, you may want to borrow someone else's ratios, like we thought about borrowing the U.S.'s because we thought our populations were similar; however, I think they are just different enough that we would want to do our own study. Because of the way each individual country's certifiers are putting things on the certificate, it is very cultural based. It is best to do your own bridge-coding studies or borrow those of a country with similar practices in certification.

C. ROONEY: That was the point I was going to make too. The two things that changed the statistics are changes in the rules and the way that doctors and other certifiers fill out the certificate. The numbers of conditions that they write, the order in which they write them, and the kind of terms they use vary enormously between countries, which is why you can get ratios that are so different. Sweden's population and ours should not be that different in age structure, sex, ethnic origin, and everything else; however, the ratio they got for the falls deaths is twice what we got. It has to do with what people write on the certificate, and those things also change with time.

L. GERAN: Lastly, one good reason to do a bridge-coding study is not only for the sake of analysis, but for the people that are doing population health analyses. It is also very important for transparency. We get a lot of media questions, and they do not understand all the technical things we do. Just to show you that they really do not, I got a media call awhile back about the introduction of ICD–10. The reporter had this idea that it was

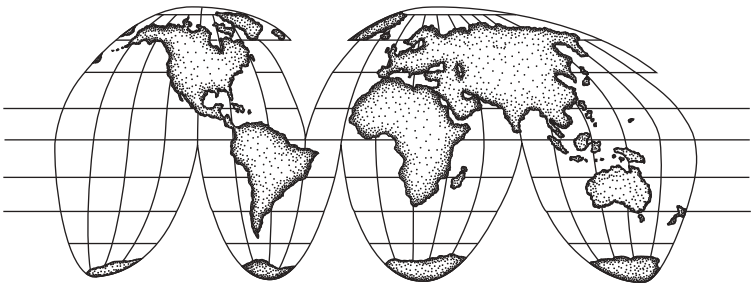
introduced because of the introduction of terrorism codes following the September 11 terrorist attacks in the United States. I had to explain to them that no, it has been a decade-long effort internationally to bring this new revision in. So where these things start, I do not know.

Following trends is a very political exercise. Our cancer society and our heart and stroke association are all battling to be Number One in the public's mind about what is the leading killer in Canada. So you want to be very careful for political reasons to make transparent what has happened in the rule revisions, and a bridge-coding study can document that.

Thank you.

SESSION 8

Data Quality



Session 8: Data Quality

Lars Age Johansson (Moderator), Board of Health and Welfare, Sweden

I remember at the first ICE, when we started talking about automated coding in Europe, that some people were under the impression that if you introduced automated coding, that would take care of all your quality problems. Now I think we have a more realistic view of things. Until we have been able to automate our doctors, we shall not have solved our quality problems. That might not be a very good idea altogether. Anyway, there are quite a few quality problems that you could solve by introducing automated coding. At least you would get an international consensus on how to apply the ICD instructions and how to use the classification, which is really quite important. Some people say that everything goes back to the way doctors certify, and that is certainly very important; however, there are a couple of studies that have shown that how we classify the deaths can bring out even more serious distortions to the data than the doctors do. So, absolutely uniform, internationally recognized classification procedures are extremely important to the comparability of mortality data.

There is much to do in the field of international comparability where classification procedures are concerned. The first presentation is by Eric Jougla, who will report on a European project about quality and comparability. You could use automated coding systems to get better comparability of data, and not just for classification. You could also use it to automate some processes directly involved in preparing the data, like querying when you return a certificate to the doctor, and what impact it has on the statistics. I will have two presentations on how querying is done, first by Graham Jackson from Scotland and then from Donna Hoyert, who will speak about querying in the U.S. system.

Once you have the automated coding, you have lots of wonderful registers that you, of course, wish to use as much as possible to assess data quality, among other things. The fourth presentation will be about the Swedish study in which we compared hospital data to death certificates and tried to assess the differences between these two.

Whether you use manual coding or automated coding, it is extremely important to always evaluate your classification procedures. The last presentation this morning will be by Finn Gjertsen of Statistics Norway and Oslo University, who will talk to us about an evaluation of classification procedures for cancer of the prostate.

The European Study of Quality and Comparability

Eric Jougla, National Institute of Health and Medical Research (INSERM), France

The aim of this presentation is to inform you about the work that is being implemented by Eurostat, the statistical office of the European Union, on comparability and quality improvement in European cause-of-death statistics. I will begin by providing background, showing you how Eurostat is disseminating and analyzing mortality data. A routine dissemination of cause-of-death data is now done by way of the Web site of Eurostat, which is called ''Newcronos.'' The available data cover various cause-of-death indicators at a national and regional level: at the national level, deaths by year and five-year age groups, standardized rates by year, all ages and premature mortality; and at the regional level—that is, the first sub-national level for each country—total and premature all-cause mortality and, by 3-year averages for confidentiality constraints, number, raw and standardized cause-of-death rates by 5-year age groups.

Besides this routine dissemination, Eurostat is also analyzing the data. One recent result of these analyses is the production of an atlas of mortality that will be published in some months. The selection of causes of death is based on the 65 Eurostat short list, that is, the summarized cause-of-death list published routinely by Eurostat. Data are analyzed in the atlas at the first sub-national level in each country. Many results concern premature mortality and mortality differences between the sexes. The atlas will be published as Volume One of the Eurostat Panorama Series on Health Statistics in 2003.

Following are some of the key results that point to the large differences in mortality existing at the regional level across countries. Figure 1 concerns premature mortality for males, all causes of death. You can note the high rates in the south of Finland, Denmark, East Germany, and in all the north regions of France and Portugal, with very large discrepancies between countries.

Figure 1.

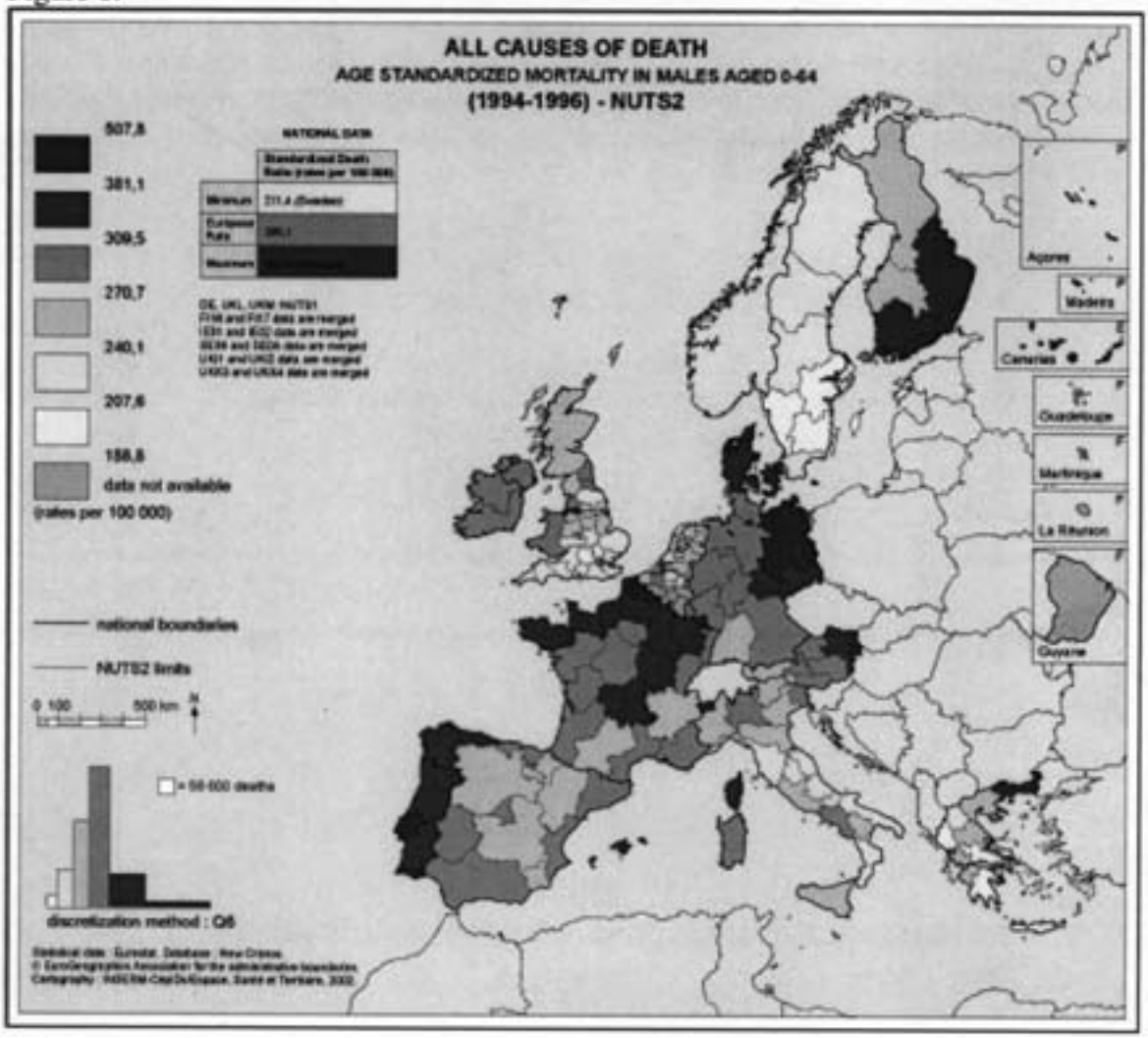

ALL CAUSES OF DEATH
AGE STANDARDIZED MORTALITY IN MALES AGED 0-64
(1994-1996) - NUTS2
507,8
381,1
309,5
270,7
240,1
207,6
188,8
data not available
(rates per 100 000)
NATIONAL DATA
national boundaries
NUTS2 limits
0 100 500 km
discretization method : Q6
Agores
Madère
Canaries
Guadeloupe
Martinique
La Réunion
Guyane

Figure 2 shows the same map for females but with quite different results. England and Wales and Denmark appear with very high levels of female mortality.

Figure 2.

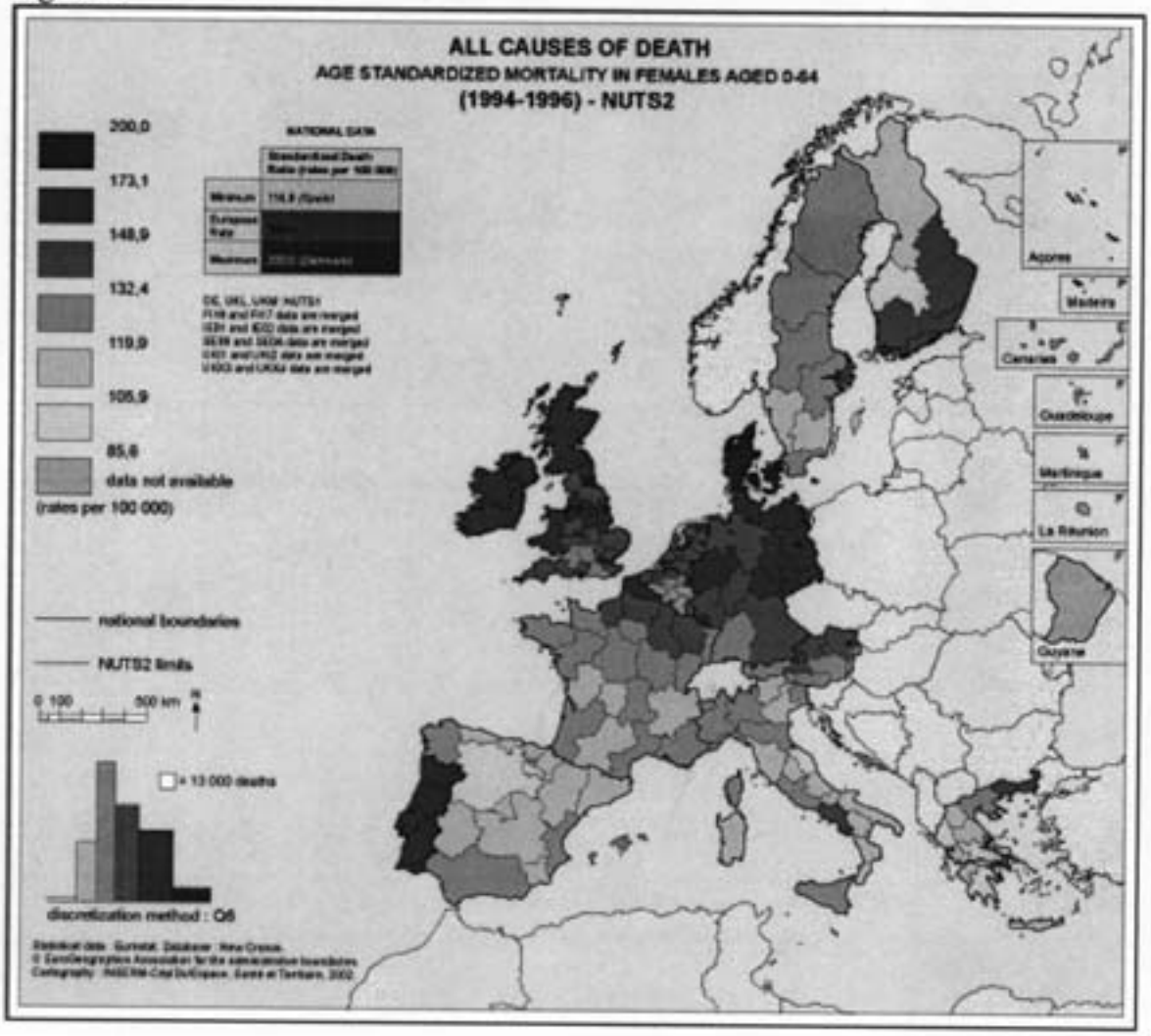
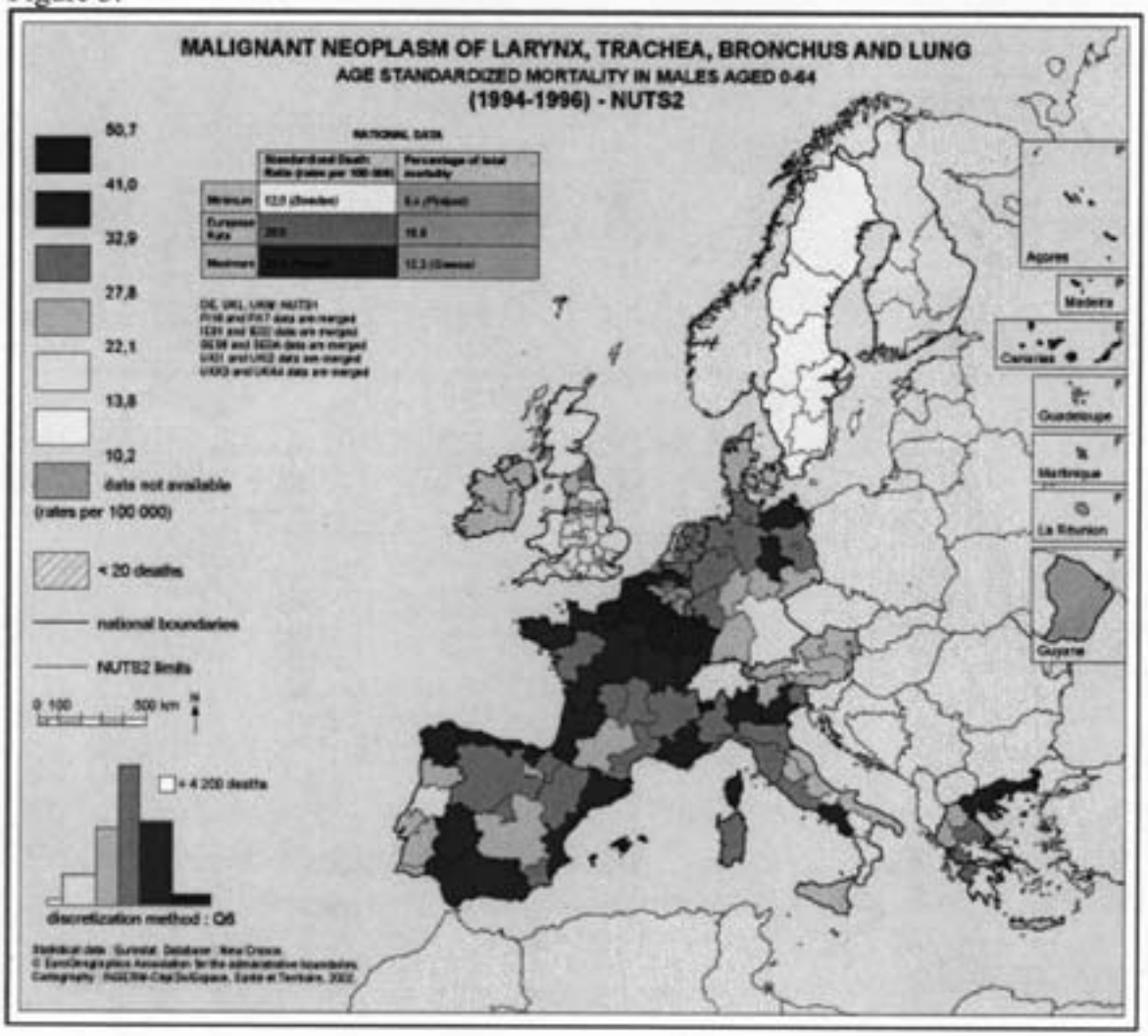


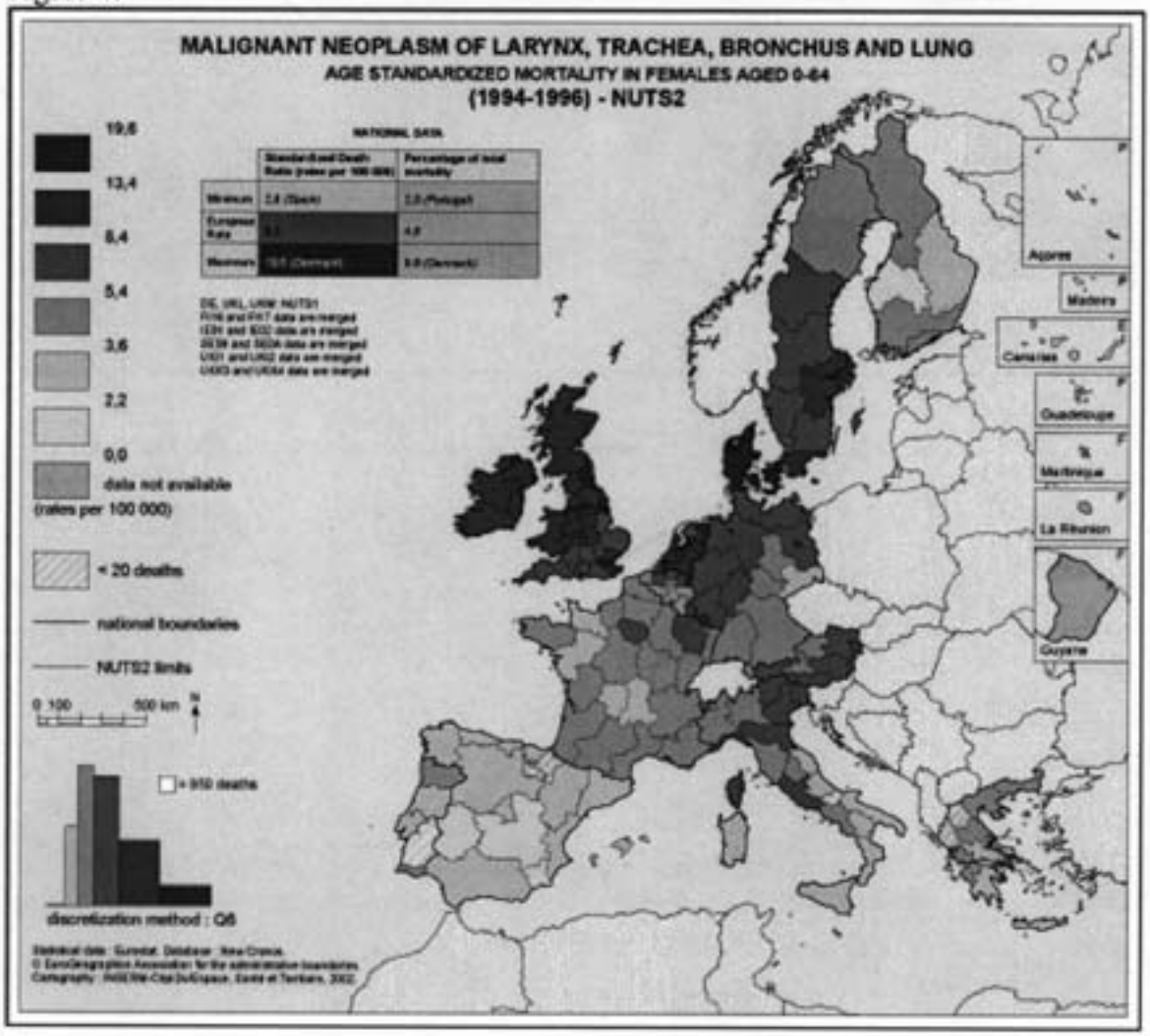
Figure 3 provides another example, lung cancer for males in terms of premature mortality, with a very clear south gradient of high rates. Many regions in France and Spain have high mortality, with the same rates as East Germany.

Figure 3.



For lung cancer for females (Figure 4), the U.K. countries and Denmark appear with very high mortality levels. For example, for lung cancer, the largest sex ratios are observed in all the regions of Spain and France.

Figure 4.



For ischemic disease (Figures 5 and 6), the patterns are quite different. For both sexes, the highest rates are observed in all the countries of northern Europe.

Figure 5.

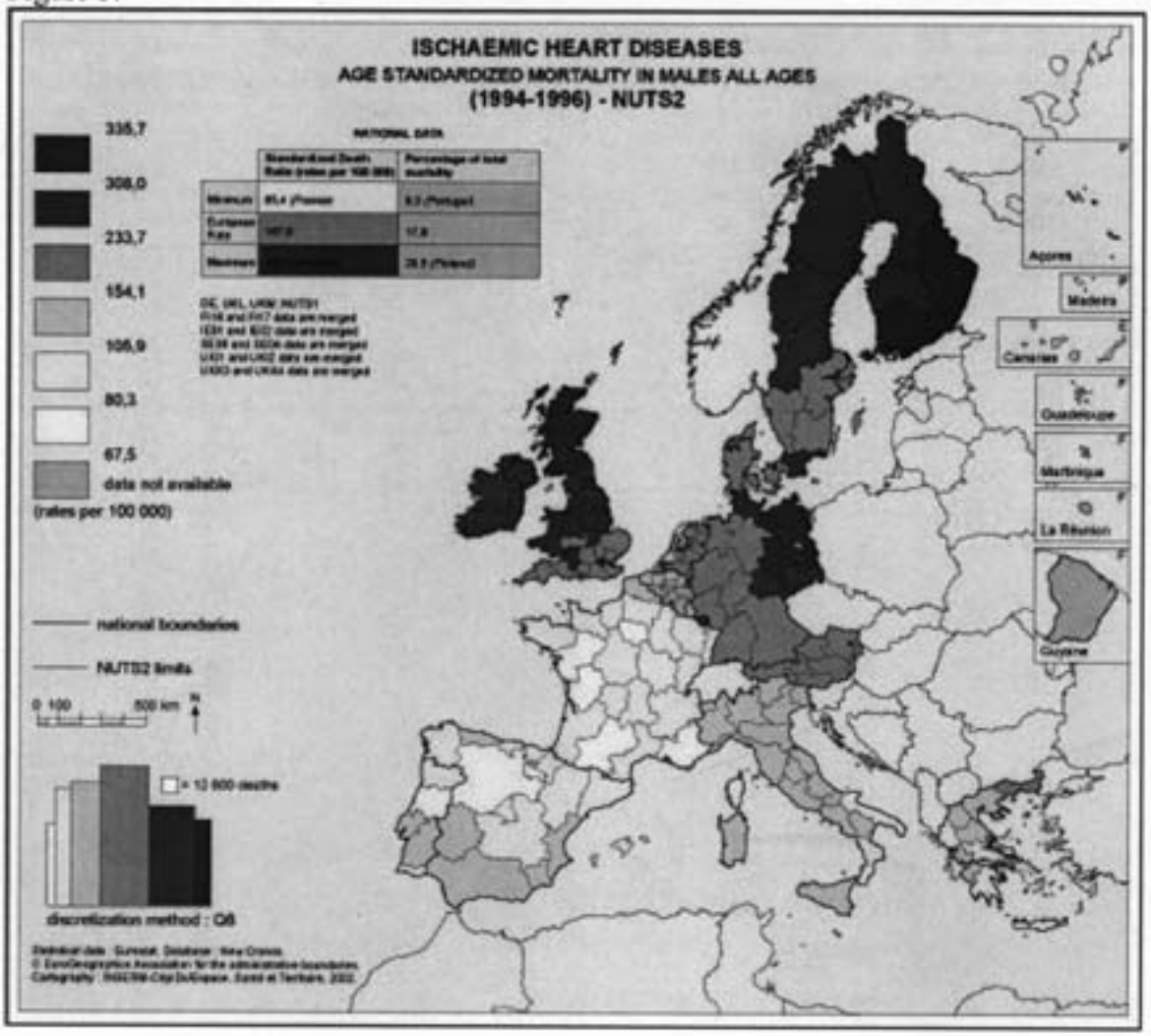
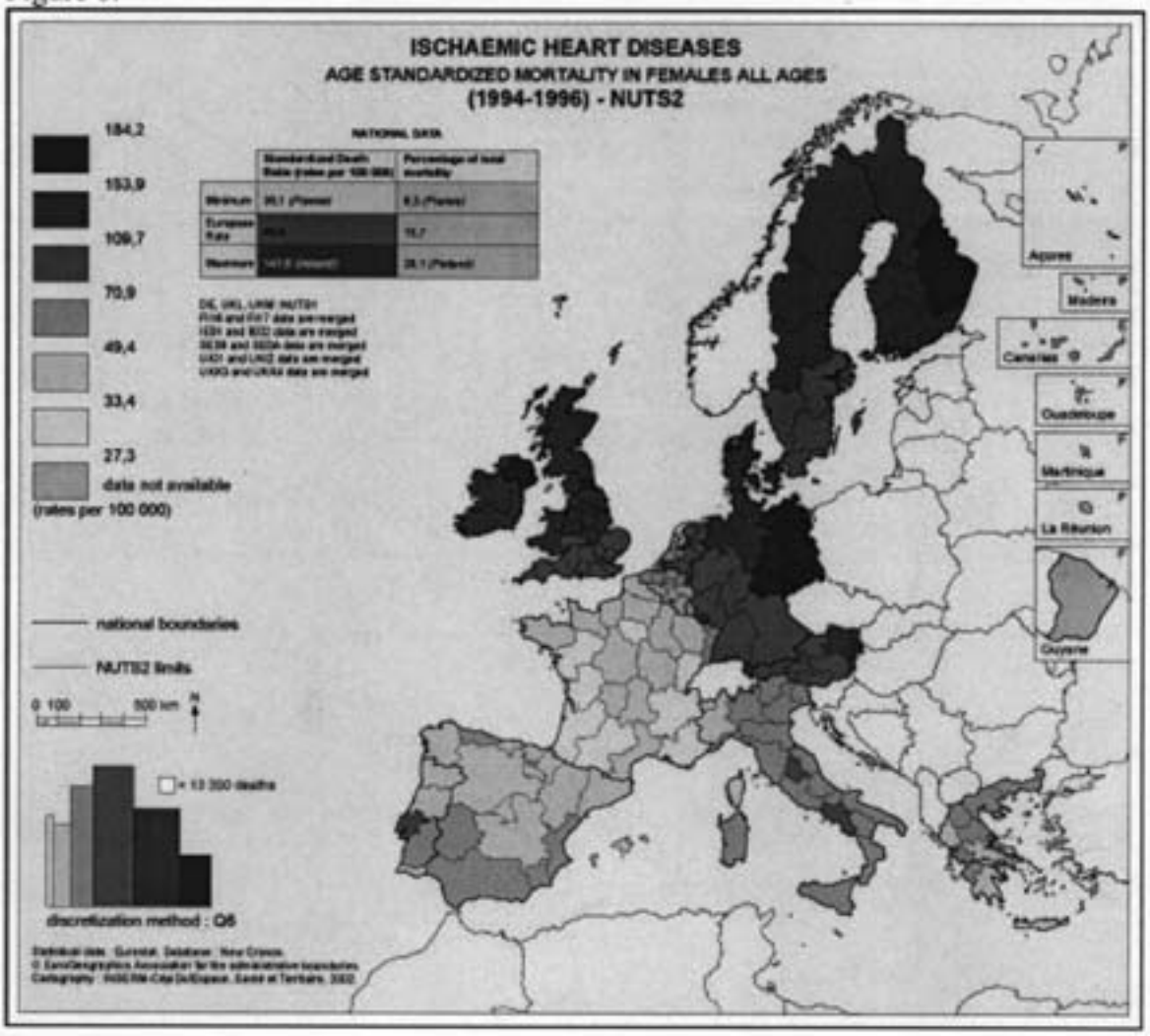


Figure 6.



These large differences in mortality level raise the question of comparability of the international data. Since 1997, Eurostat has implemented considerable work focused on the assessment and improvement of the quality and comparability of data. These studies have been conducted in the framework of a specific task force whose overall goal is to improve the collection, analysis, and dissemination of comparable cause-of-death statistics within the European Union. Three topics are followed through time: certification of causes of death, coding of causes of death, and the methods of production of harmonized indicators. The organization of the task force is based on two meetings by year, specific technical meetings, and a global working group by year gathering all the countries.

I will present the work on certification of causes of death, but you know that there are also at the moment additional works on comparability of coding practices. For codification of causes of death, there are two basic Eurostat reports that can be downloaded from the Web site of the European Union. For certification practices, the basic report is called ''Comparability and Quality Improvement in European Cause-of-Death Statistics.'' This report has been coordinated by CépiDc–INSERM in France in the framework of the Eurostat Task Force, and financed by the DG Sanco health monitoring projects of the European Community.

The report is divided into three sections:

- The first section is called ''Knowledge Base on the 65 Causes of Death,'' and it includes two types of materials: a large review of studies published on the international comparability of causes of death, and a synthesis of the methods used to analyze and measure the potential biases in comparability and the way to take into account these biases, with a focus on specific causes of death.
- The second section of the report describes the certification practices in each country. The results are based on the analysis of a questionnaire that was presented to each member state. Monica Pace presented this questionnaire previously.
- The third section is a very important part of the report that consists of 39 recommendations to improve the comparability of cause-of-death statistics in the European Union. These recommendations have been approved by all States.

Through the international literature review, we have identified about 500 papers linked to the problem of the international comparability of causes of death, many of them coming from the U.S. and U.K. The most frequent types of causes of death considered in these studies are neoplasms, suicide, diabetes, and AIDS.

As an illustration, I would like to summarize some results concerning diabetes. We spoke of diabetes yesterday, but we were focusing on coding and multiple-cause analysis. Now we deal with the variability in certification practices for diabetes. These results are not recent but are still interesting.

Table 1 is based on an analysis of death certificates from different countries involving diabetes. The first column indicates the proportion of certificates where there are more than four conditions reported in the death certificates. It ranged from 8 percent in Belgium to 50 percent in Germany. The reason for the low figure for Belgium is that there was no Part Two of the death certificate in Belgium. You can see directly the impact of this different form of death certificates on the amount of medical information entered on the certificate.

The second column presents the proportion of death certificates for which the ICD general rules can be applied. That means that the death certificate was well completed. This proportion ranges from 66 percent in Belgium to almost 100 percent in Northern Ireland.

To investigate differences in certification practices, there is a recognized method that consists of writing a limited set of case histories and completing death certificates corresponding to these case histories by random samples of physicians in each country. If you look at the international literature review, summarized in Figure 7, you will notice that these types of investigation are still rare and concern few causes of death like cancer, respiratory disease, and diabetes.

Table 1.

CERTIFICATES WITH DIABETES - 1989

Country	> 4 conditions reported (%)	Possibility to apply the ICD General Rule (%)
N Ireland	14	96
Scotland	10	92
Netherlands	28	86
Rep Ireland	18	84
France	32	64
W Germany	54	60
Switzerland	36	52
Belgium	8	36

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Figure 7.

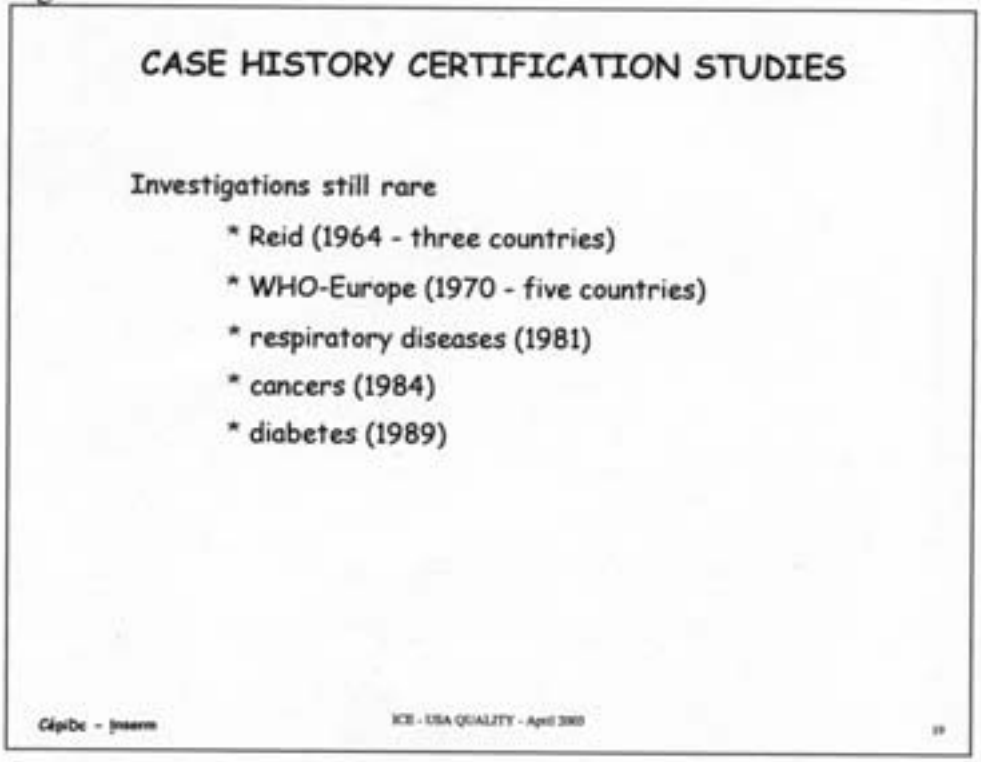

Table 2 shows the results of a study focused on diabetes. This study was based on the certification and coding of ten case histories. The first column presents the proportion of cases for which diabetes is reported by the physician on the death certificate. It ranges from 84 percent in Scotland to almost 100 percent in Germany. The second column presents the proportion of cases where diabetes is considered as the underlying cause of death by the physician. It ranges from 21 percent in France to 35 percent in Germany.

Table 2.

CASE HISTORY STUDIES DIABETES (1989)

Country	Diabetes reported by The physician	
	On any line (%)	Underlying cause (%)
W Germany	96	35
Rep Ireland	89	32
Netherland	86	30
Switzerland	92	28
Scotland	84	28
N Ireland	86	28
France	87	21

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Coming back to the Sanco project, the questionnaire to each country was aimed at documenting and analyzing the general differences in certification practices. One of the aims of the work of Monica Pace is to disseminate this questionnaire in all the new candidate countries.

The 39 recommendations, agreed by all member states, must act as a framework for effective implementation in future Eurostat works. The main topics covered by these recommendations are as follows: coverage of causes of death, including the problem of people dying abroad, confidentiality problems, organization of the cause-of-death statistics offices, perinatal cause-of-death certification, general cause-of-death certification, querying practices, and training practices for certifiers.

To conclude, I want to stress the importance of these recommendations for the future work of Eurostat. The first recommendation is recommendation 33 of the report: creation of a basic training course package developed as an international reference on certification. An Italian team is at the moment coordinating this work in the framework of Eurostat. Another recommendation that we want to tackle very soon concerns improvement of the coverage of causes of death in cases of violent death because in many countries there is a lack of feedback after legal inquiry.

Thank you.

Queries in the Scottish Coding System

Graham Jackson, General Register Office, Edinburgh, Scotland

In Scotland we have similar, but not identical, registration and data collection arrangements to England and Wales. One of the key differences currently is that we follow up a number of cases each year using what we call ''medical enquiries.'' For many years, my department has used these medical enquiries to seek additional information on the cause of death for a proportion of all deaths. The enquiries take the form of a letter to the doctor who was responsible for completing the medical certificate of cause of death.

There are two main reasons for issuing such a followup letter: 1) when we are told that a postmortem examination/autopsy is planned (but has not been performed at the time the certificate was completed) and, therefore, we know that additional information is likely to become available; and 2) when the information provided is in some way imprecise or inadequate for accurate cause-of-death coding.

In this presentation, I will be giving a brief overview of the approach we use in Scotland to seek this further information. I should stress that this is not rocket science; it is a very straightforward procedure. Nor is it unique; some other countries do very similar things. Its main virtue is, of course, that it is a simple way of improving quality.

The system used up to 1995

Until the mid-1990s, production and issue of these followup letters was a purely clerical procedure. Needless to say, it was relatively time-consuming. The information obtained from each death that was registered, including the full cause-of-death text, was sent to us on a paper form. It was checked and scrutinized by coders and they then entered the appropriate ICD codes. Information about whether a postmortem examination had been or might be carried out was included on this form, so it was relatively obvious when the first type of medical enquiry had to be issued. However, deciding to issue the second type of enquiry was very much dependent on an assessment by the coder as to whether it fell into a number of categories that we wished to follow up.

Although word processing templates were used, preparing the letters was essentially a manual process. All of the letters were checked by one of the senior coders before being issued and, because time is important in this type of followup, we tried (but did not always succeed) to issue the letters on a weekly basis.

Introduction of semi-automated system

In 1996, we introduced a new computer system for handling all of our information on vital events. This was a substantial new development, a major reason for which was to include the automated cause-of-death coding software. The introduction of the new system was made possible because information on an increasing number of the vital events registered, including deaths, was being submitted to us electronically (on diskette) by our local registration offices.

The information collected electronically covered most of what was required to generate the medical enquiry letters. The key items are as follows:

- age, gender (and other demographic information)
- full cause-of-death text
- status of autopsy/postmortem
- name and the address of the certifying doctor
- for deaths in hospital, the name of the consultant responsible for the patient and the address of the hospital.

This last item is particularly important because, particularly for deaths that occur out of normal working hours, the death certificates may be completed by relatively junior hospital doctors who do not have the full

information at hand about the particular case. So when we go back to try to clarify information on such deaths, we contact the person who is more likely to have the complete information, which is normally the consultant in charge of the relevant department.

We use the information on age to limit the issue of the followup letters. We do not follow up deaths aged 85 and over because, in the past, we have had a relatively poor response rate from doctors for such cases, even when the cause information has been rather vague.

The first type of followup letter

The sample letter below, which we use to seek additional information following an autopsy/postmortem, is a relatively straightforward word processed document that is generated automatically.

> CERTIFYING DOCTOR: Dr Fiona Ross
>
> Dear Doctor
>
> On the medical certificate issued for the death detailed overleaf you indicated that you might be in a position to give additional information as to the cause of death, either as a result of a postmortem or otherwise. I should be grateful if you would provide me with such information to assist in the statistical classification of cause of death. Any information you supply will be treated as strictly confidential and will not lead to amendment of the death certificate or the public record.
>
> Yours sincerely
>
> SUSAN COLE M.D., F.R.C.O.G., F.F.C.M.
> Cnsultant Adviser in Medical Statistics

I would like to make a few comments about this letter. Firstly, it is issued under the signature of our consultant medical adviser. We are sure that this is a good idea, as it is likely to give a better response than if it comes from a fairly anonymous administrator, or even a statistician like myself. Secondly, we make it clear that the additional information supplied will not appear on the final death certificate. Whilst it will be stored in our database—and used to improve the cause of death codes—it will not become part of the official record. This is particularly important in Scotland as all of the cause-of-death information reported on the death certificate is part of a public record that can be seen by anyone who wishes to purchase a copy.

You will see from the wording that we also state that the doctor may have indicated that additional information might be available other than from the autopsy/postmortem. About 10 to 15 years ago, we added an extra box on the medical certificate of cause of death, where doctors could indicate that they might have additional information that they would be willing to supply to us later on a confidential basis. This box was mainly introduced to try to get more accurate information about AIDS deaths because we had found that doctors were sometimes rather ‘‘economical with the truth’’ when it came to a death where AIDS was involved. No doubt this was because it was deemed to be something that might be sensitive for the bereaved family. We also hoped that this might help for some drug-related deaths, where rather vague terms, rather than terms specific to drug abuse, were sometimes used for similar reasons. In fact, the introduction of this box was not a great success as it was not greatly used. However, we have kept it on the form because it still helps on a number of occasions.

On the back of the letter, we simply give the details of the deceased and reprint the original cause-of-death text in the standard layout—four lines in Part I followed by Part II. Beneath this we have a space where they can complete new Parts I and II, should they wish to amend what was supplied originally.

The second type of followup letter

The following is an example of the second type of letter. This is slightly more complicated in that it involves some sort of specific question to the doctor. In this case, it asks whether a tumor was malignant or benign. You will also note that, following best survey practice, we supply a prepaid and addressed envelope to help to keep our response rate up.

CERTIFYING DOCTOR: Dr Fiona Ross

Dear Doctor

With reference to the death detailed overleaf, I should be grateful if you would provide me with further information to assist in the statistical classification of cause of death. Any information you supply will be treated as strictly confidential and will not lead to amendment of the death certificate or the public record. Can you say whether the tumour was malignant or benign?

Please insert your reply in the space overleaf and return the form at your earliest convenience in the prepaid envelope enclosed.

Yours sincerely

SUSAN COLE M.D., F.R.C.O.G., F.F.C.M.
Consultant Adviser in Medical Statistics

Here are some further examples of standard questions which can be generated by the system.

- Can you confirm that the tuberculosis was active?
- Can you specify the primary site of a carcinoma?
- Can you specify the cause of the obstruction? Was it due to malignant disease?
- Was this an embolism due to pregnancy, childbirth, or the puerperium?
- Can you specify the cause of the
- – hepatic failure?
- – renal failure?
- – septicemia?
- – jaundice?
- Can you specify the disease or condition which necessitated surgery?

When we introduced ICD–10, we reduced the number of standard questions of this sort, mainly in one area. We were getting a relatively poor response to requests for a more specific cancer site, particularly within one organ. In ICD–9 terms, we still had high proportions of fourth-digit code nines for several cancers despite the medical enquiries. The followup letters might reduce the proportions from around 90 percent to around 80 percent. However, before we changed the system, we talked to our cancer research experts. There is a very good cancer registry in Scotland, and it was agreed that for detailed research into cancer, better information could be supplied by them from the clinical records.

Importantly, the system we use allows the coders to amend a question, or add a supplementary question, to the letters when the case is being processed. It even allows them to override the system so that a letter is not produced automatically. An example might be where it is clear from the wording in the text that information would not be available. For instance, we will often seek further information on the primary site of a cancer; however, if we have some information on the certificate about secondary cancers and the doctor explicitly states ''primary site unknown,'' we will not follow that up because it could be seen as slightly annoying and wasteful of time.

Finally, as in the past, all of the letters are scrutinized by a senior coder before they are issued.

Numbers of letters issued

Now here is some summary information on the numbers of letters issued, etc. In 2001, some 4,800 medical enquiries were issued, roughly half of each of the two types we have been looking at. The enquiries involved some eight percent of the 57,000 deaths in Scotland, in 2001; 80 percent of the enquiries were returned.

I should perhaps point out here that we do not pursue nonresponse. Experience has shown that the overwhelming majority of the nonresponse is for cases where the doctors did not have additional information, and it is seen as an annoyance if we pester them further.

Of those returned, approximately half led to a change in the cause of death codes, and of these, approximately three-quarters involved a change to the underlying cause, frequently at the third- or even the second- character level in ICD–10.

I had hoped to give a more detailed analysis of the effect of the system, but in doing the preparation work for this talk, I discovered that the audit trail in our database was not quite as good as I had hoped it would be. Though we keep all of our original text and all of the final text, we do not keep the original codes as calculated by the system. We just keep the final sets of codes, so it is difficult to give a precise figure for the types of deaths which involve medical enquiries. However, I can give you an indication of which chapters had relatively high proportions and which had relatively low proportions of followup.

I do not think any of this will be too much of a surprise. We had relatively high proportions in Chapter I— Infections; Chapter XI—Digestive System (often concerning blockages and so forth); Chapter XIV— Genitourinary System; and Chapter XVI—Perinatal. No one will be surprised that there is a high proportion of follow-ups for the external causes, Chapter XX.

Of course, balancing this, there are chapters where the proportions are relatively low. That is particularly the case for Mental and Behavioral Disorders (Chapter V); Circulatory System (Chapter IX); and Respiratory System (Chapter X). One reason why the respiratory chapter registers a particularly low level is that it is one that affects very many old people, and of course, we have a cutoff at age 85.

Other medical enquiries

In addition to the semi-automatic followups I have described, we have specific mechanisms in place to clarify cause of death for a number of specific, difficult-to-code groups. I will mention these quickly to give an indication of the other quality-control measures that we take.

We follow up sudden infant deaths in great detail, both with the hospitals/pathologists and with a charity that is very closely involved in monitoring such deaths in Scotland. We also have a medical enquiry that is specific to drug-related deaths. I mentioned earlier that doctors sometimes do not give the whole story in relation to drug-related deaths. Typical examples include cause-of-death text limited to ‘‘inhalation of gastric contents’’ or ‘‘pulmonary edema.’’ When this happens to a relatively young person, we follow it up as there is a significant possibility that it may be a hidden drug-related death. Stocks of the form used for this followup are also held by the four main forensic pathology departments in Scotland. They all complete additional information on drug-related deaths for us and submit this automatically for every death they deal with that appears to have been drug-related. These procedures have certainly greatly improved our information on drug-related deaths in the last 5 years.

The final two categories, road traffic accidents and homicides, are categories where going back to doctors does not really help much. We have a good relationship with the relevant statistical collection agencies, and each year we carry out comparisons of the information they hold on road-traffic-accident deaths and homicides, to try to make sure that the two different data sets, when published, are not too radically different. There are, inevitably, definitional differences, but as long as we understand the differences, that helps the analysis.

Some conclusions

The semi-automatic approach to generating medical enquiries has reduced the workload, and it has certainly ensured a more speedy issue of the followup letters. As I said previously, that is quite important. We definitely consider it worthwhile. As can be seen from the general figures I gave earlier, a substantial number of coding changes result; we believe, of course, that most of these are improvements.

By focusing very much on the vague terms that are sometimes used by certifying doctors, we manage to reduce the number of R99 codes to a very low level in Scotland. I did not have the figure to hand when I came here, but I looked it up yesterday so that I could fill in Cleo Rooney's questionnaire. In 2001, we had 75 R99s out of 57,000 deaths, which is 0.15 percent.

We believe that issuing the letters may have some positive educational value for the certifying doctors. It reminds them of the things they have done that are not quite good enough, and hopefully next time they might give us a more complete answer. Considering these issues would assist in the development of prompts for electronic death certification software. Measuring the true effectiveness of such measures requires a good audit trail. As I mentioned earlier, we need to improve this in Scotland. My final conclusion, however, is that I am certain that our system of medical enquiries improves the quality of the information held in our database, and that is the key issue.

Thank you.

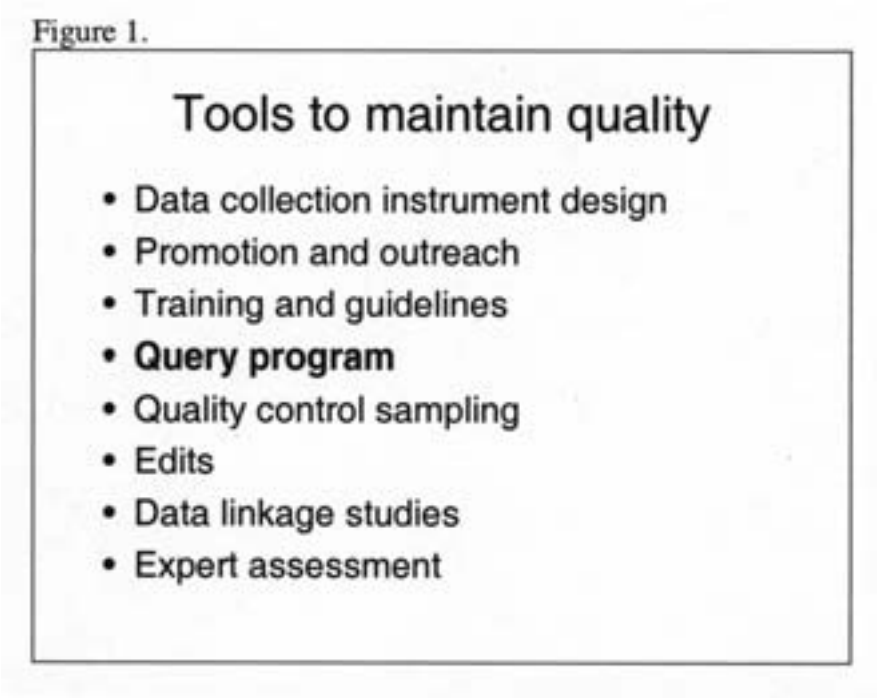
Queries in the United States

Dr. Donna L. Hoyert, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

Introduction

This presentation is about querying mortality data in the United States. Querying is but one of a number of methods used to maintain data quality, as shown in Figure 1.

Figure 1.



A query is a procedure used to contact the certifier who completed the death certificate to clarify or obtain further information. The purpose of querying is to obtain information needed to make mortality statistics as complete and accurate as possible, and to educate certifiers about the proper method of completing the death certificate.

Since the U.S. vital statistics system is decentralized, the responsibility for querying rests with each of the 50 States, New York City, the District of Columbia, and the U.S. territories. In 2002, 38 States reported that physicians provide additional information without prompting, although this occurs rarely in 17 of these States. Consequently, there is a need to actively solicit additional information. Moreover, NCHS has contracts with each State that requires querying.

Description of querying programs in the United States

All States, with the exception of one, query either demographic or cause-of-death information. In the case of demographic items, all but two query. In the case of cause of death, four States do not query. The number of States querying cause of death has increased over time.

NCHS produces two separate instruction manuals that give guidance on how to request additional information for querying. The Part 18 manual focuses on demographic items while the Part 20 manual focuses on cause of death. Each manual is intended to serve as a model that can be adapted by the States.

We recommend a combination of querying performed on a random basis and querying directed to records with apparent problems, but we acknowledge that States must weigh benefits for improving data against resource limitations. As it turns out, the States weigh how much directed querying that they will do, rather than whether they will also do random querying.

In the case of cause of death, NCHS divides recommended queries into six levels of descending priority, as shown in Figure 2. The situations identified in Priority Level One are ones for which it is imperative that further information be solicited, yet they still only involve about 5 percent of records. Each successive priority level identifies situations for which querying would be useful but is less imperative. Querying all priority levels is desirable to ensure specificity and completeness in the physicians' statements of cause of death. However, not every State will be able to devote the same amount of effort to querying.

Figure 2. Levels of Cause-of-Death Querying in the U.S.

Level	Goal of priority level
1	• Verify reported rare conditions • Obtain primary site/character of neoplasms • Ask for reason for surgery/medical care • Ask about injuries without mention of external causes • Ask about improbable sequences • Ask about conditions suggestive of HIV when HIV is not mentioned
2	Ask if conditions not usually considered to be an underlying cause arose from other conditions
3	Obtain more detailed information to classify to more detailed ICD category
4	Determine site/location to get more precise code
5-6	Improve precision at 4th digit level

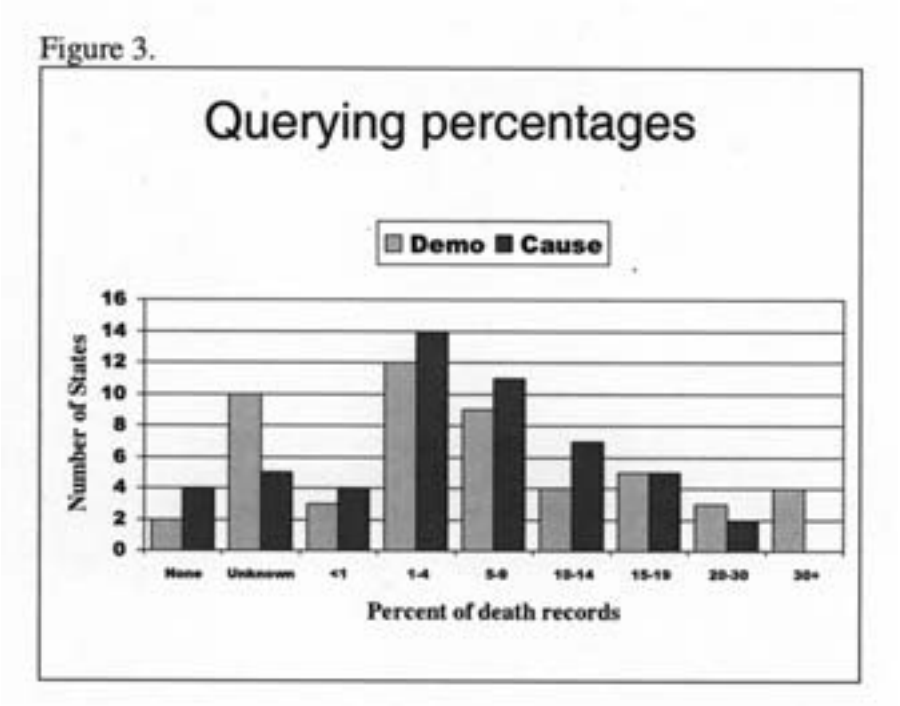
The contracts between NCHS and the states for 1995–1999 required querying at the two highest priority levels. The contracts for 2000–2004 require querying of rare causes, which is one of the scenarios specified by the highest priority level. The States tend to follow NCHS guidelines but have State-specific reasons for which they query. Few have extensive programs.

The scenarios mentioned by States as the most common reasons for querying are as follows: ill-defined conditions; primary site of cancer; missing information, particularly in the case of injury; reasons for surgery; and illegible or incomprehensible entries. The missing and incomprehensible scenarios are more basic than those that we set out in the NCHS guidelines. The other common scenarios are all examples of NCHS' highest priority level.

The scenarios queried in the one State for which queries are conducted by a medical examiner are quite distinct from the rest. The criteria for querying in this State involve more judgment about the quality of reported sequences and the appropriateness of one individual being the certifier over another.

In the U.S., about 4 percent of death records are queried because of cause-of-death issues (Figure 3). States vary widely in the proportion of records queried with the range between less than 1 percent and 30 percent, with most concentrating in the 1–4 percent range. Nationally, in 2002, the percent of records queried is about the same as in 1989. In addition to asking the certifier for clarification or additional information, some States get additional information from other sources. The most common of these alternative sources is to use traffic-accident reports to fill in missing information.

Figure 3.



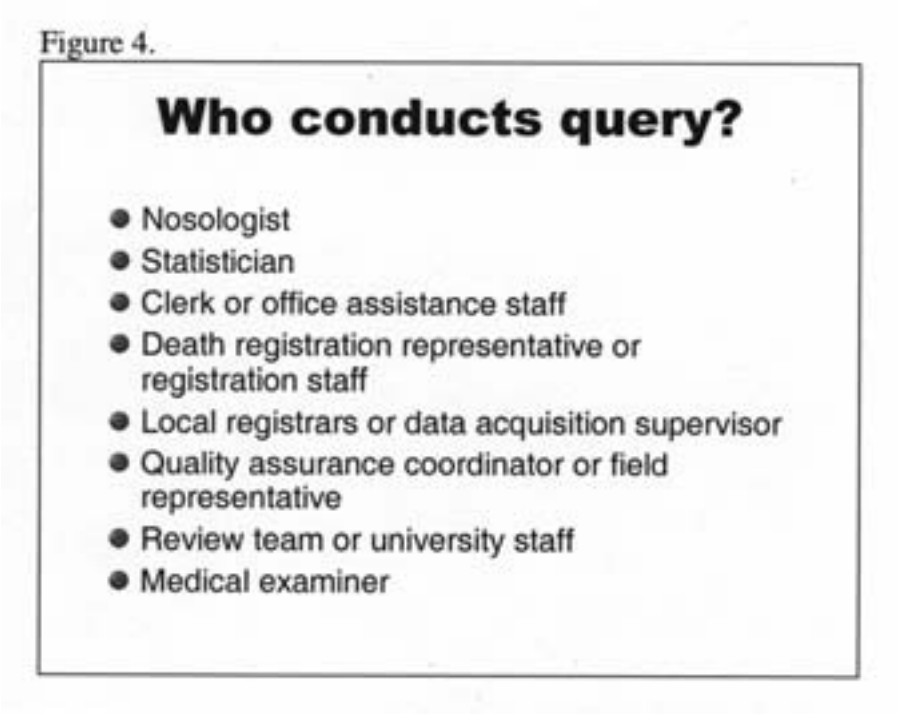
We recommend that queries be conducted by sending a relevant form letter, a copy of the information reported on the death certificate, and other informational material for educational purposes. The letter should request details to enable proper coding of the specific death certificate, but also provide information so that the certifier will correctly report similar deaths in the future. Telephone communication is assumed to be a way to follow up or clarify the questions. The majority of States indicate that cause-of-death queries are primarily conducted by mail. However, there is more variety in the mode of conducting queries now than in 1989.

NCHS does plan to incorporate Priority Level One queries into the automated software. Initially, the automated system would identify the certificate number, the query level, and the recommended letter. State staff would then pull the record and review if the query is warranted. A second-stage development would result in the system producing a letter that may be used to query the record. However, NCHS does not have any schedule for when these changes will be made to the system.

In the absence of an option in the NCHS software, the States must identify which records need to be queried on their own. I cannot quantify the number of States by the type of approach used to identify records, but I can give two examples of methodology. In one approach, States review every certificate to determine when a query is necessary. In another approach, the States have individually developed computer programs that identify certificates that may need to be queried. A staff person then reviews the records selected by the computer to decide if the query truly should be conducted.

Historically, State nosologists have queried cause of death, but automated processing systems have resulted in fewer States having nosologists. In recognition of changes in staffing resources, we expanded the recommendation to include nosologists, statisticians trained to query, or medical officers with an understanding of how death certificates should be completed. In fact, as shown in Figure 4, a variety of people conduct queries in the States, although queries are most commonly conducted by nosologists.

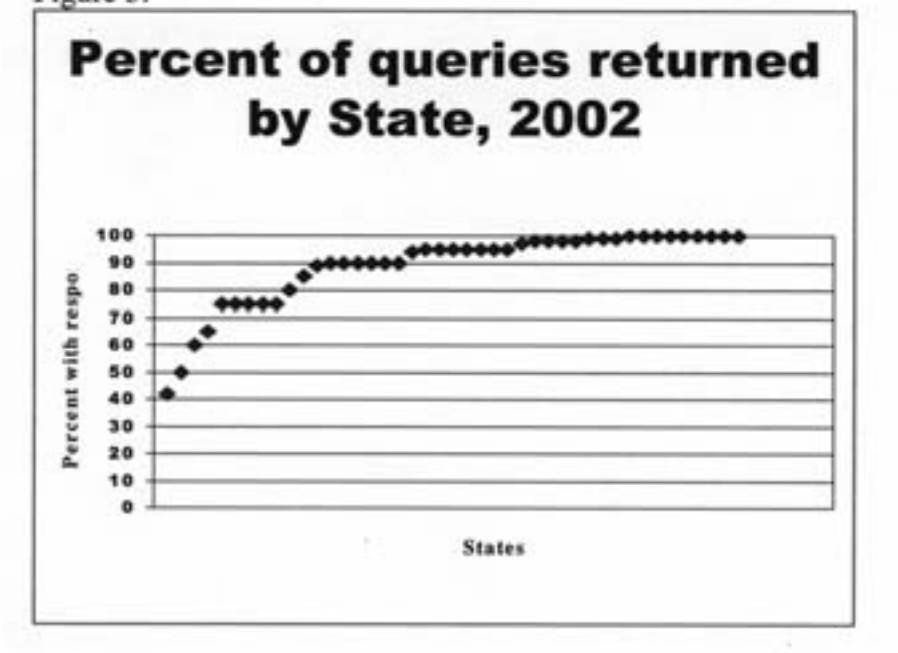
Figure 4.



Normally, cause-of-death queries are directed to the certifier who originally provided the information in the medical section of the death certificate. However, if the death occurred in the hospital, it is also possible to obtain additional information from the hospital files to further clarify the cause of death.

States generally report good compliance with query letters. Overall, about 87 percent of queries are returned with a range between 42 and 100 percent for individual States, as shown in Figure 5.

Figure 5.

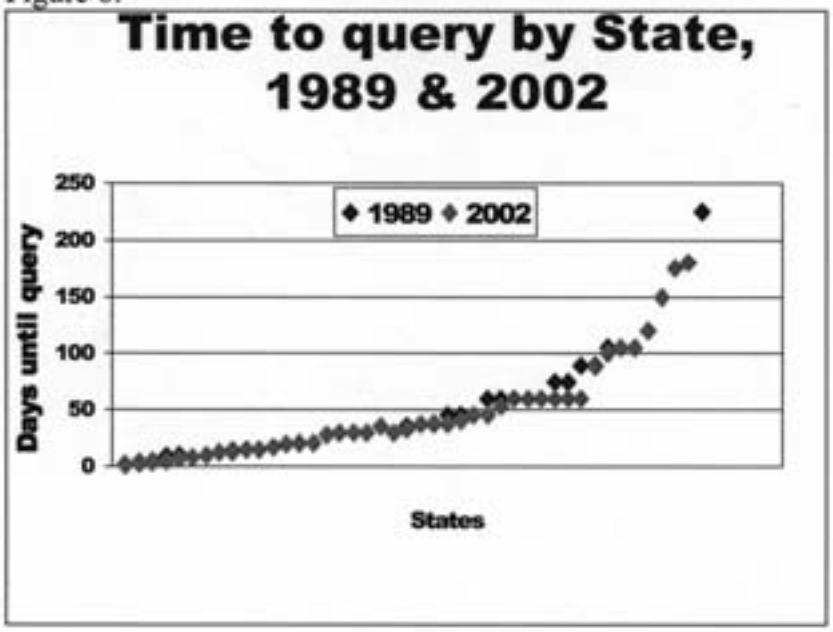


In sum, underlying cause changes for about 68 percent of the queried records. Additional information is obtained for about 12 percent of records without changing the underlying cause, and the remaining records are unaffected as a result of the query. Again, the results vary for individual States.

States also vary with respect to how they incorporate the information obtained through querying. For legal reasons, no changes or additions are made on the face of the original record without the approval of the legally designated certifier. However, most States include the changes as amendments to the records, at least in certain circumstances, while the remaining States use the additional information only for statistical purposes.

Time intervals are an important factor in querying (Figure 6). In 1989, the average time for States to query was 52 days. In 2002, the average was 49 days. Minimizing the time between when the certifier fills out the certificate and is queried improves response rates and affects the information obtained.

Figure 6.



Supplemental information for two States

I have chosen two States to show the effect of querying on a more detailed level (Figure 7). The causes shown are commonly queried in these States. This demonstrates that the percent of queried records for which the underlying cause changes varies by cause and by State.

Figure 7.

Effect of querying

	Percent reassigned to another underlying cause	
Causes	**Oregon- late 80's**	**Washington St- 1995-2001**
Organ failure/ill-defined & non-specific causes	---	49
Renal failure	55	---
Septicemia	49	---
Cardiac arrest & arrhythmias	56	69
Dementia, NOS	---	76

--- Data not available

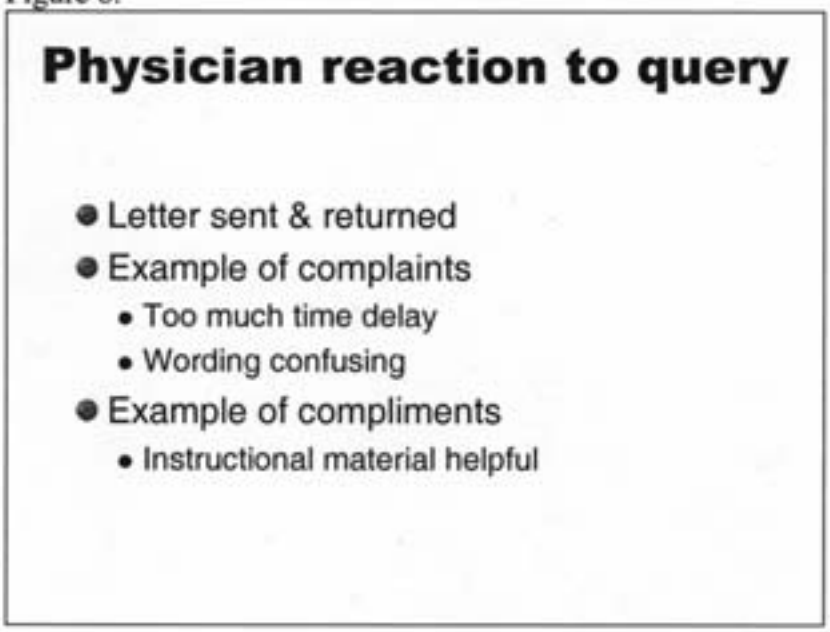
In the past, the most common concern voiced by the States had to do with getting information from coroners. However, problems in dealing with nursing homes and medical residents who may relocate before the query is conduced have also been mentioned.

States do modify queries in response to physician reaction. The States try to balance the goal of obtaining more specific information against irritating physicians and having physicians report false information to avoid the query.

A query that causes problems in one State does not in another. For example, Oregon eliminated some NCHS-suggested queries for congestive heart failure and mental conditions in the 1980s, either because the queries did not prove useful, or physicians responded negatively. In the case of Washington State, congestive heart failure queries were useful, and were not objectionable to the physicians, but Washington did also drop most queries for mental disorders because responses did not usually alter the selected underlying cause, and the State was concerned about physician response.

Since NCHS does not perform the query, we do not get a sense of the range of the physician reactions. Those that we hear about tend to be critical. For example, we hear individuals complaining about specific cases, time delays, focusing on misspellings and information entered into the wrong location rather than the content of the cause, queries conditioning physicians to report false information, and selected immigrant physicians who state that we are too lenient in the U.S. and should be tougher on the physicians.

Figure 8.



We can get a more comprehensive picture by looking at Washington State's experience (Figure 8). Typically, the interaction is straightforward. A letter is sent and returned, possibly with some telephone communication to clarify issues. The response rate is better if the number of days between the date of death and date of the query is held to a minimum. For the last 7 years, Washington State has been querying close to 6 months after the day of death, and the most common complaint from certifiers concerns the time delay. For several specific query letters, certifiers complain or raise issues, so Washington State has responded by trying to clarify the wording of the specific letters. Other responses are more idiosyncratic and do not have larger implications for the query program, such as a couple of certifiers who have been very irate or apathetic, and refused to work with the state to resolve their issues. Not all the atypical interactions with certifiers are negative. Washington State has received compliments about instructional material included with the query letter.

Conclusion

Querying has proved to be a valuable activity. With 4 percent of records queried, we almost meet our goal of having a burden of 5 percent of U.S. death records queried. Most queries receive a response, and a majority of the queries result in changes in the underlying cause. In part, their effectiveness is by design. The States query blatant errors and winnow out questions that do not seem helpful. In most cases, the interaction is quiet and straightforward. It is the exception for physicians to react in an unusually positive or negative fashion. However, it does seem that outlier complaints are more common than outlier compliments.

The disadvantages of querying are that it is costly, takes up staff time, demands time from the certifying physicians, and has the potential for setting up confrontational situations.

Specifications developed to assist states to implement the newest revision of the death certificate and subsequent work on the re-engineering of vital statistics support the idea of querying, but they possibly reduce the volume of querying by taking care of problems before the state gets the data. Specifications that define edits to incorporate into electronic death registration systems should greatly reduce the need to follow up with queries on demographic items and eliminate some cause-of-death queries. Many cause-of-death queries are not addressed in the specifications, so there will be a continuing need for cause-of-death queries even after a successful development of electronic death registration systems.

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Comparing Death Certificates and Hospital Discharge Diagnoses—Can the Differences Be Explained?

Lars Age Johansson, Board of Health and Welfare, Sweden

This presentation is about an attempt in Sweden to assess the quality of the mortality data by comparing the death certificate data to hospital discharge data. This was very much inspired by the Oxford Record Linkage Study, which is a classic in this field. Using records of all kinds for people living in the Oxford region for 30 years back, they published some very interesting studies in which they compared hospital discharge conditions with what is written on the death certificate. The main conclusion of these studies was that hospital diagnosis and cause of death do not always agree, that is, you do not always die from the condition for which you are treated.

We tried to repeat this study in Sweden with a larger database than the Oxford Linkage Study. We used the National Hospital Discharge Register in which we have every hospital discharge in the entire country and, of course, the National Cause-of-Death Register. In 1995, we had about 94,000 deaths. About 70,000 of those had also been admitted to hospital during their last year of life, and 40,000 of those died at hospital, which corresponds to 43 percent.

The question was, ''What was the agreement between their last discharge diagnosis and their cause of death?'' Of course, the agreement varied much with the cause of death. For neoplasms it is quite high, especially for people who died at hospital. If a malignant neoplasm is your last discharge diagnosis, then the likelihood that that is also the cause of death is quite great. On the other hand, we had zero percent agreement for the pregnancy deaths. That is partly because we had only three pregnancy deaths in that year, and all of those went to different categories of the Basic Tabulation List.

We found that the agreement between the hospital discharge diagnosis and the underlying cause decreased quite rapidly once the patient had been dismissed from hospital. Even if they died the same day, the diagnosis was quite different once the patient was outside the hospital doors. The reason for that, I believe, is that if somebody dies in hospital, it is quite often the same doctor who writes the discharge record and who issues the death certificate. Once the patient gets out of the hospital, another doctor will take care of him/her and may assess the case differently.

Like the Oxford researchers, we found that basically there are three groups of conditions. First (1), there is one group of main discharge diagnoses that are also often the underlying cause of death, namely dramatic conditions like a rapid cancer in young people, acute myocardial infarction, or accidents of different kinds. (2) We have a second group of discharge diagnoses that are quite often mentioned on the death certificate, but as contributory cause of death. They include pulmonary embolism, renal failure, and misadventures in medical care. (3) There is also a group of conditions that, even though they are the main discharge condition, they are not reported on the death certificates. Those are partly symptoms and partly chronic conditions. Even a really serious condition like chronic obstructive lung disease was quite often left off the death certificates.

The questions we asked ourselves were: ''When the main diagnosis is reported only as a contributory cause or not reported at all, would that indicate an error in cause of death certification? Could we possibly use this as a kind of quality measure for mortality statistics? Or might there be other explanations not quite as exciting?'' Of course, one part of the explanation could be that we are dealing with different definitions. I suppose that everybody in this room is familiar with the definition of the underlying cause of death, ''the disease or injury which initiated the train of morbid events leading directly to death.'' In contrast, the main discharge diagnosis was defined in ICD–9 as the condition diagnosed at the end of the episode of health care as being primarily responsible for the patient's need for treatment or investigation. Of course, these two might differ.

We realized that we could not just look at whether the diagnoses were the same or not. Rather, we had to check whether they were compatible or not. We also found when we did our first study that quite a few very interesting conditions had been left off the death certificate. There were cases where people had been admitted to hospital 2 or 3 days before death, perhaps because of a fractured neck or a skeletal fracture, and these fairly

drastic events had not been mentioned on the death certificate. So we would also like to assess the impact of such non-reported conditions.

We tried to define the different cases you might see, that is, the different relationships between main discharge diagnosis and the underlying cause of death. If they are the same, then there is certainly no reason to suspect some kind of quality problem. Of course, both could be wrong, but that is not our main problem, I think.

You could think of cases where the reported underlying cause agreed quite well with the last main diagnosis, namely, you could consider the last main diagnosis a complication of the reported underlying cause. If somebody has pneumoconiosis as the underlying cause and the last hospital stay is for pneumonia, that would make sense. It also would if the main discharge diagnosis was a symptom of the reported underlying cause. So if we have a ruptured ulcer of the duodenum as the underlying cause, and the hospital discharge diagnosis was abdominal pain, that agrees quite well.

Then there could be cases where things do not agree that well. For instance, say that somebody who died at hospital had pneumoconiosis as the main diagnosis, but the underlying cause was myocardial infarction. What happened? Or if somebody got pneumonia as the underlying cause, and the last main diagnosis was something chronic and longstanding like chronic obstructive airway disease. These cases might be more interesting to investigate more closely.

We went back to our 1995 data, our 40,000 hospital deaths, analyzing them by the Basic Tabulation Lists in ICD–9, which has about 250 diagnostic groups. We did it by using ACME.

First, to check the compatibility between the last main discharge diagnosis and the underlying cause of death, we made up death certificates for the test. We assumed that in a normal case you would have your underlying cause for some time, but if you were admitted to hospital, this could be for the last complication of this underlying cause. So we made up death certificates with the last main discharge diagnosis as the direct cause of death, and then we put the reported underlying cause as the explanation of that last diagnosis.

We put this through ACME, and if ACME accepted this sequence, then we would say that these two cases are compatible. In these cases, the differences in reporting to the hospital discharge register and the mortality register does not give us any cause for concern. Of those 40,000 deaths, 54 percent did not agree. We found that according to ACME, one-third of these 54 percent were also incompatible, which means that ACME did not think there was a reasonable medical connection between the two. That corresponds to about 15 percent of all deaths in a year in Sweden.

We checked the impact of data left out. Cleo Rooney said that everybody in this room should know Rule Three. I agree. If by chance there is someone in the room who does not know Rule Three, it is a way of correcting death certificates where the physician has entered the true underlying cause in Part II. Then you could in certain circumstances apply Rule Three and say that what the physician actually wrote in Part I of the death certificates is an obvious consequence of this serious condition in Part II.

So what we did in this case was to keep the death certificate as we had it, but add all the conditions from the hospital discharge register to Part II. We placed them last in Part II, after the conditions that the doctor had actually reported there. If ACME changed the underlying cause, we would draw the conclusion that the doctor had indeed omitted important information. We found that this was true in 8 percent of all deaths in Sweden. We also found that this new underlying cause that ACME would now select had been reported as a contributory cause in 23 percent of cases. You might wonder why ACME did not pick it up the first time. That was because from the hospital records, we got information on, for example, recent surgery, which we did not have on the death certificate. If somebody has recent surgery, you would reclassify, for example, heart failure as a complication of surgery, and that would lead to a reselection of underlying cause of death.

We also found more specific language in the hospital records than on the death certificates. I think that has to do with the situation in which doctors report to the hospital discharge register. Swedish doctors are required to themselves enter a detailed ICD code, which they have to look up in the ICD volumes and then choose something quite specific. However, when they write the death certificates, they use their clinical everyday language without the same detail.

So what happened when we added those hospital conditions to Part II? Misadventures and mistakes in medical care went up by almost 1,000 percent. At first, I did not really trust our figures; however, at about the same time as we concluded this study, a couple of studies were published in the United States and Britain where they reported quite severe underreporting of misadventures in medical care. Perhaps our figure is somewhat closer to the truth than the one in the medical mortality register.

Alcohol went up by almost 500 percent, which is perhaps not a surprise, either. Relatives object when doctors put down alcoholism on the death certificate. For accidental falls, you will find that in almost 40 percent of the cases, the physicians had not reported a recent fall on the death certificate. I suppose they just expect old people to stumble and fall, which is an ordinary event at old age.

There are, of course, quite a few problems with a study like this one. First, we do not know very much about the quality of the hospital discharge register. There have been a few attempts at evaluating the Swedish hospital register, and the main outcome was that it is not as catastrophic as some people would like to believe.

Of course, we have the problem of multiple causes. Perhaps you remember the example of somebody with myocardial infarction and pneumoconiosis. It is quite possible for people to have quite different but independent diseases, and one of them might be the correct underlying cause and the other one the correct discharge diagnosis.

We also have a problem with ACME Decision Tables. While we in Sweden agree with the ACME Decision Tables in about 96 percent of the cases, those 4 remaining percent might account for quite a few of the discrepancies that we have seen. Then, of course, there is the time gap. We cannot really apply this methodology to people who happen to leave hospital before they died. I think that is quite clear from our results.

The next step in this study will be to try to review the medical records from both cases where we believe that the main discharge diagnosis and the underlying cause of death are compatible and cases where we do not think they are compatible. We have collected about 1,200 medical records that we will review to see whether or not they agree with the death certificate and with the hospital discharge record.

The problem we are now facing and trying to solve is to evolve some kind of methodology for how to do this evaluation of the medical records. We are not interested in having one physician making a subjective assessment of the record just to replace another subjective assessment of the record. We are trying to develop a protocol for how to read these medical records and abstract the crucial data. Perhaps I will be able to get back to that at the next ICE meeting.

Thank you very much.

High Mortality of Prostate Cancer in Norway: Information and Codification Bias?

Finn Gjertsen, Statistics Norway

Introduction

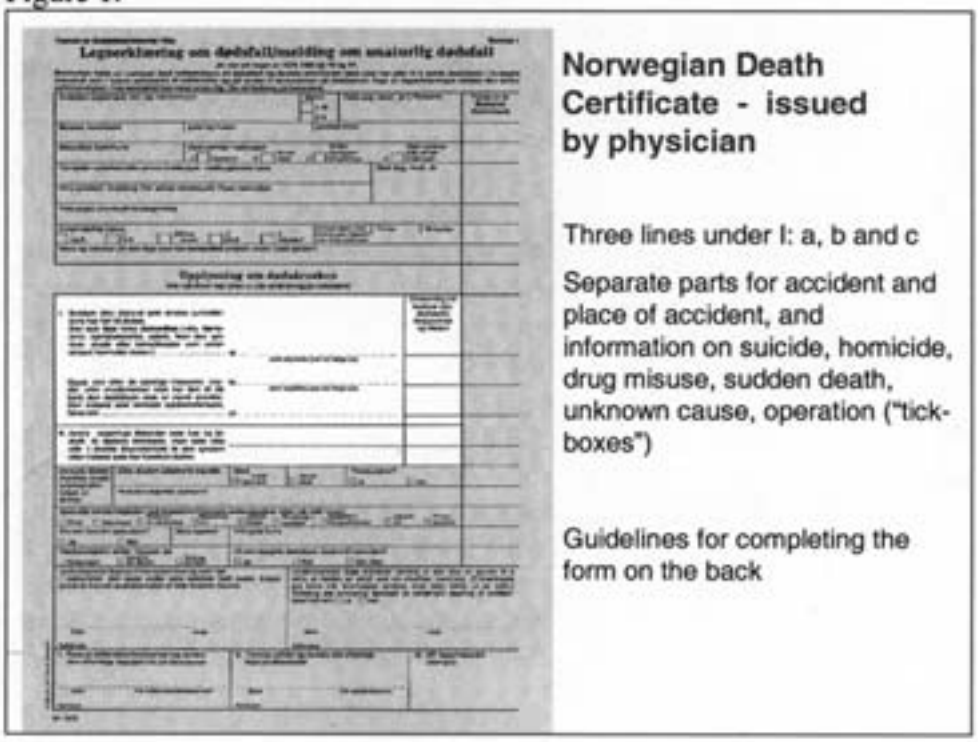
I am going to provide the background for this project, briefly describe the Norwegian system, and then focus on the project. The main question we addressed in this project was, ‘‘What is the impact on official mortality statistics of using sources other than the death certificates?’’ As you all know, we can divide the process affecting the quality and comparability of the statistics into two main groups: the information basis and the handling of this information.

As in many countries, or maybe all countries, the official cause-of-death statistics are based on information from the death certificates issued by physicians, and additional information from physicians in files and results from autopsies. Like other countries in Europe, Norway also routinely uses information from the Cancer Registry of Norway and the Medical Birth Registry of Norway as sources for the classification and coding of cause of death. The cooperation in the data exchange between the Cancer Registry and Statistics Norway was established in the 1950’s, so there is a long history behind this. Today, we use a manual, computer-assisted coding system. With multiple-cause coding, we can code up to seven codes. ICD–10 was implemented from 1996 data.

Figure 1 shows the form we use in Norway. We have not implemented a fourth line because the process to change the form has been very slow. We started a project to do that in 1996 or 1997, but the new draft has not yet been approved.

The system in Figure 2 shows an overview of the information basis for the Norwegian cause-of-death statistics that will not be discussed in detail. The main focus for this project is on how we are handling the information, and on routine data from sources other than the death certificate.

Figure 1.



Norwegian Death Certificate - issued by physician

Three lines under I: a, b and c

Separate parts for accident and place of accident, and information on suicide, homicide, drug misuse, sudden death, unknown cause, operation ("tick-boxes")

Guidelines for completing the form on the back

Figure 2.

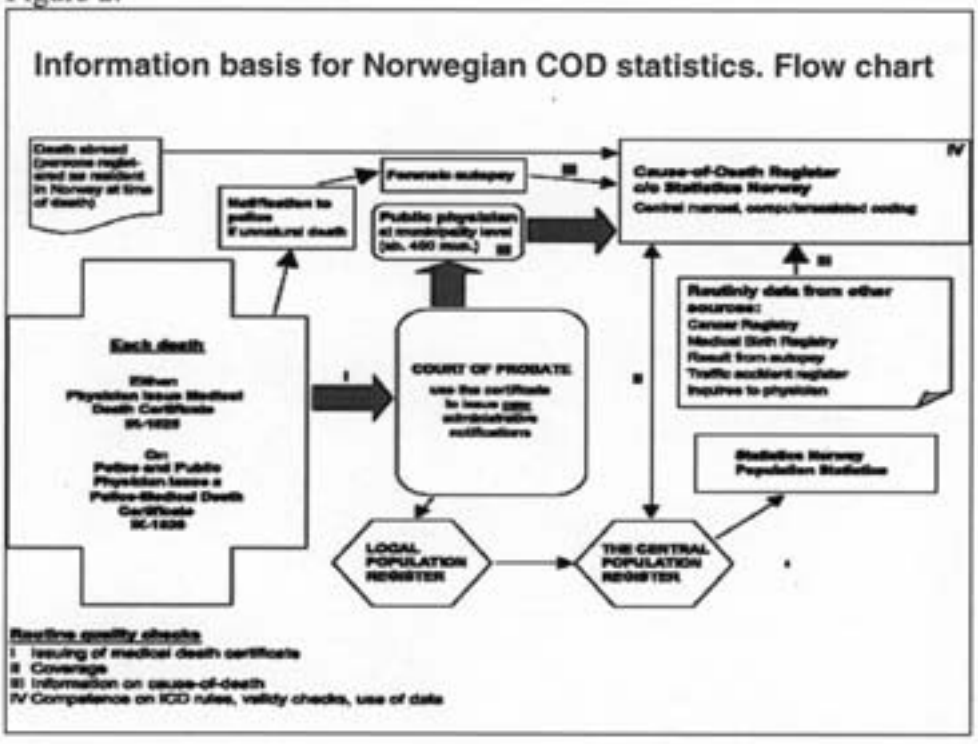
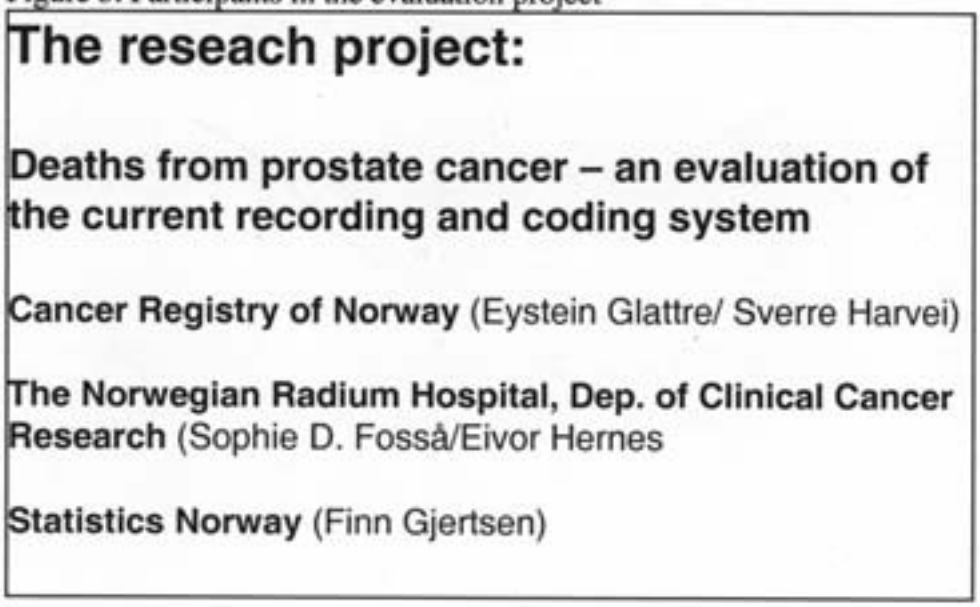


Figure 3. Participants in the evaluation project

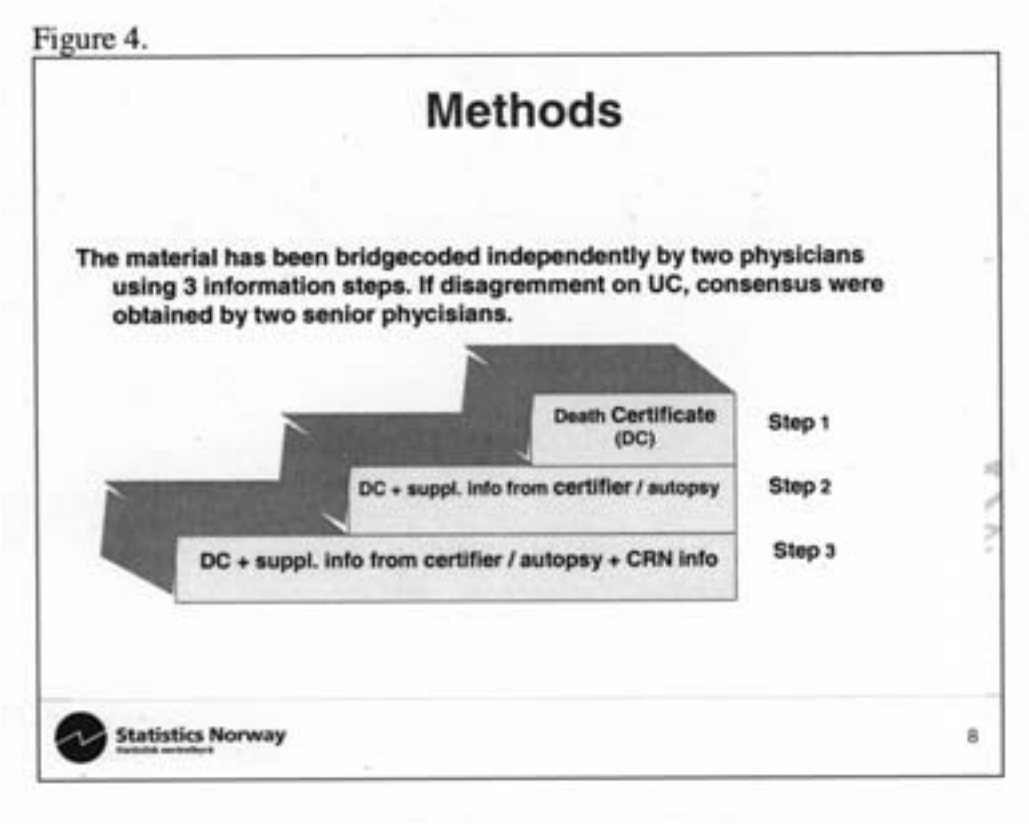


This research project was initiated by the Cancer Registry of Norway and the Norwegian Radium Hospital, Department of Clinical Cancer Research, so there are many persons involved in this, as shown in Figure 3. The objective is to try to assess a possible effect of using additional information from the cancer register on official mortality statistics of prostate cancer in Norway. Also, we want to try to assess the effect of using a manual versus automated coding system.

Methods

The material we have used includes all deaths in 1996 with prostate cancer registered in the cause-of-death register. This was possible because we have a multiple-cause coding system. The method we used was to review and recode all the information that was obtained and used by Statistics Norway in the codification process of the 2,000 cases.

Figure 4.



The material was divided into three groups and was recorded independently by two physicians using the three steps shown in Figure 4. If there was a disagreement in the coding of underlying cause, consensus was obtained by two senior physicians, and one of them is the medical advisor for Statistics Norway. In the first step (1), they only used death certificate information; in the next (2), they used death certificate plus information from the files of the certifier file and from the answers in autopsy results; and in step three (3), they also used information from the cancer register.

Figure 5.

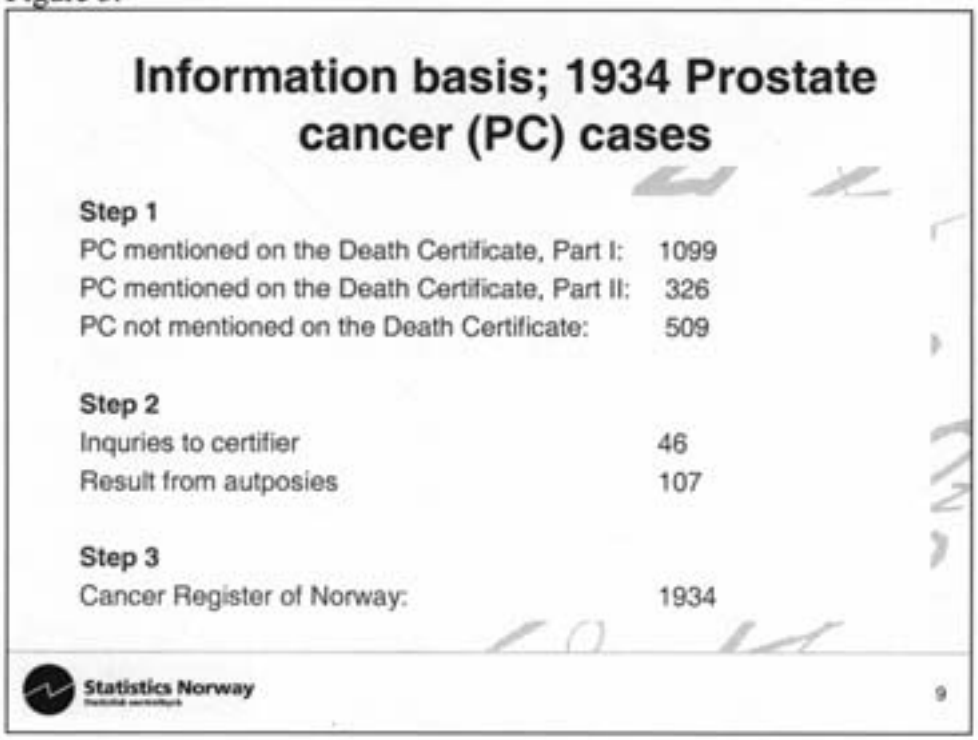
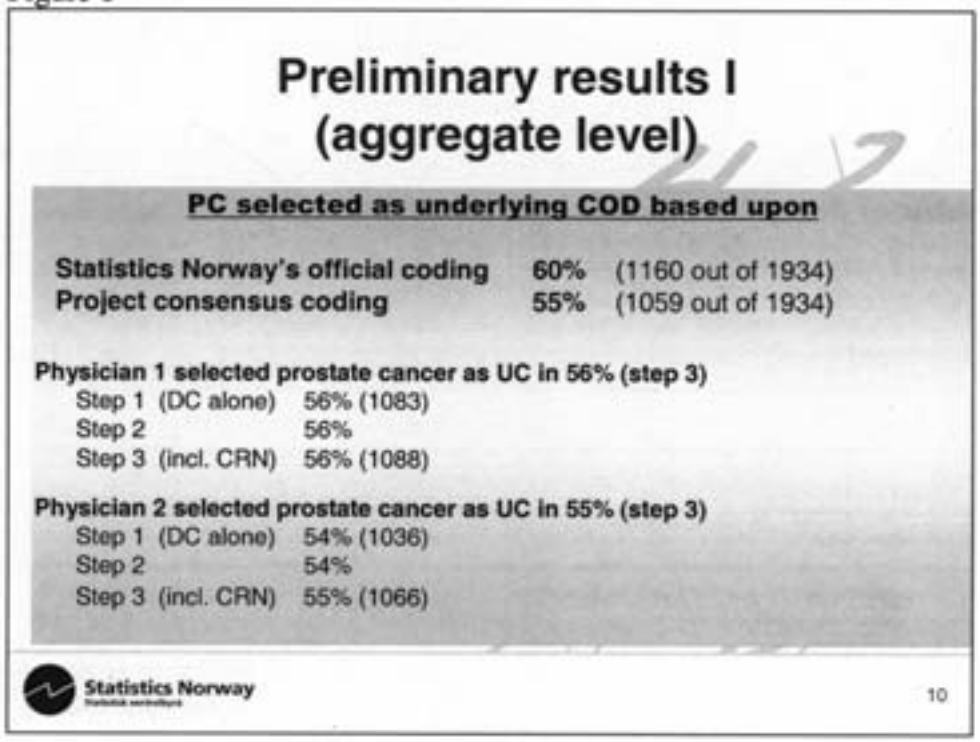


Figure 5 shows how many of the total cases were mentioned on the death certificate. There was some additional information from steps two and three. So in step 3 there was information for them all, in step 1 there were about 500 without information on prostate cancer, and in step 2 there were about 160 cases with some additional information.

Figure 6



Results

Statistics Norway selected 60 percent of the 2,000 cases as underlying cause. The project selected 55 persons, about 100 less. If we compare Physician 1 and Physician 2, we see that the difference is very, very small. Even if you go from step one to step three, it does not have much effect. If we go to the case level and compare Statistics Norway with the project consensus, the agreement was 93 percent. Between Physician 1 and Physician 2, the agreement was 95 percent.

Discussion

Use of information from the Cancer Registry may lead to increased mortality from prostate cancer compared with countries where research information is not routinely used or available. Preliminary results can explain only partially the relatively high mortality from prostate cancer in Norway. Physicians have to come up with other explanations. Maybe it has something to do with the service and the time during the diagnosis.

We also plan to compare the coding system we use with the automated coding system. We want to evaluate impact of the manual versus the automatic coding system and use ACME on the selected prostate-cancer cases. This project has not yet started, but we have done some testing, so we know that it will be possible to carry out this study. This will be done in cooperation with the National Board of Health and Welfare in Sweden.

Thank you.

Query and Explaining High Mortality—Taiwan Experience

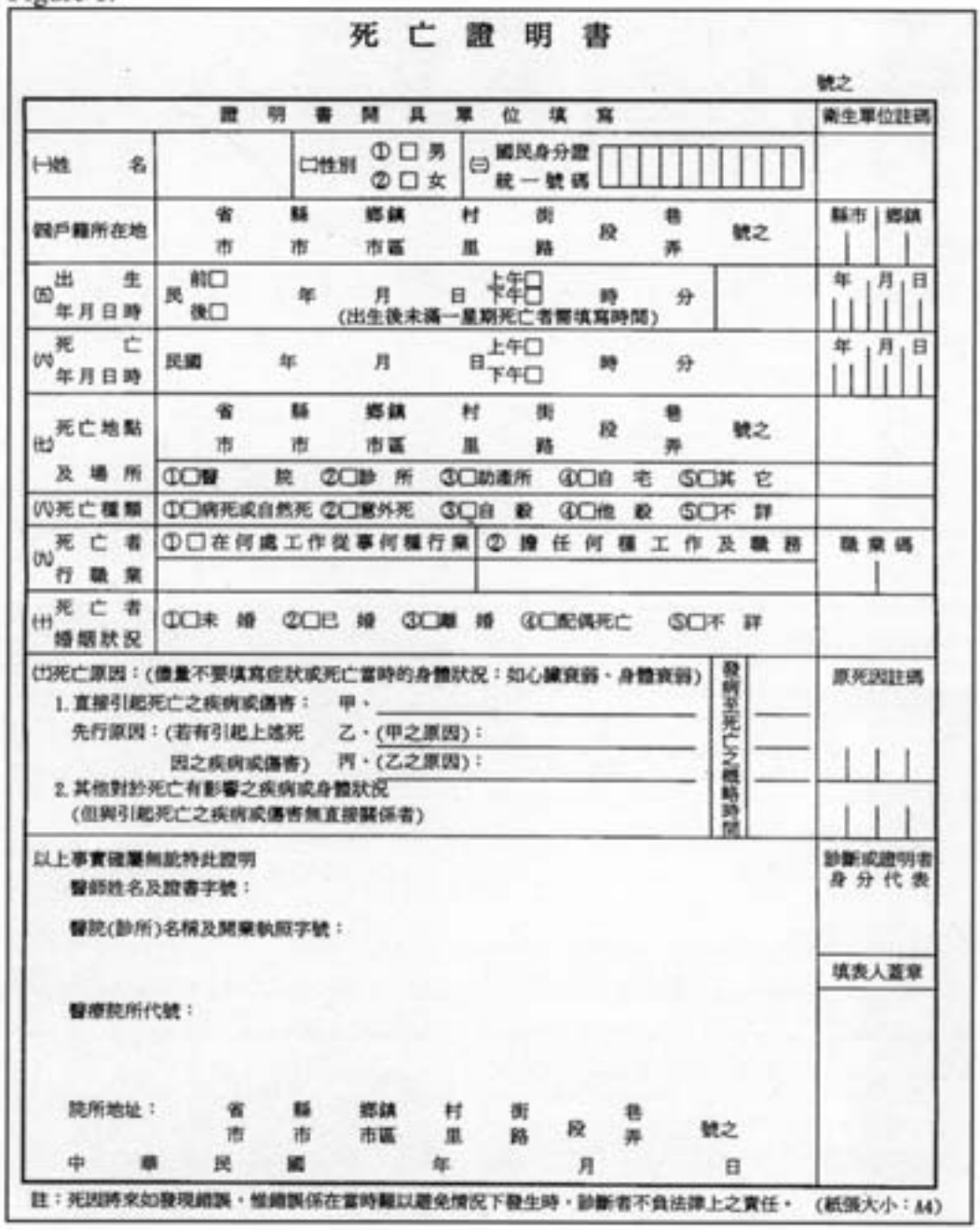
Tsung-Hsueh (Robert) Lu, M.D., M.P.H., Chung Shan Medical University, Taiwan

I attended the ICE meeting in 1996, and I learned a lot from that meeting. I want to share some of our experiences in Taiwan concerning quality of cause-of-death data. I distributed among you some of my papers. The first one is a paper published in the *International Journal of Epidemiology and the Journal of Epidemiology and Community Health*. I also did a study trying to explain why diabetes mortality is high in Taiwan. The third paper concerns querying in Taiwan, and I will present some of the data from that study.

Unlike most of you who work in government, I am in academia, so I am a user of mortality data. When I used the data, I developed a lot of questions, which stimulated me to participate in improving the quality of these data, so now I am also involved in producing the mortality data in Taiwan.

Figure 1 shows the death certificate for Taiwan in Chinese. Because the certificate does not offer very much space, sometimes the doctor writes a long diagnosis onto another line, and we do not know whether the diagnosis belongs to the first line or the second. That is a problem.

Figure 1.



死亡證明書

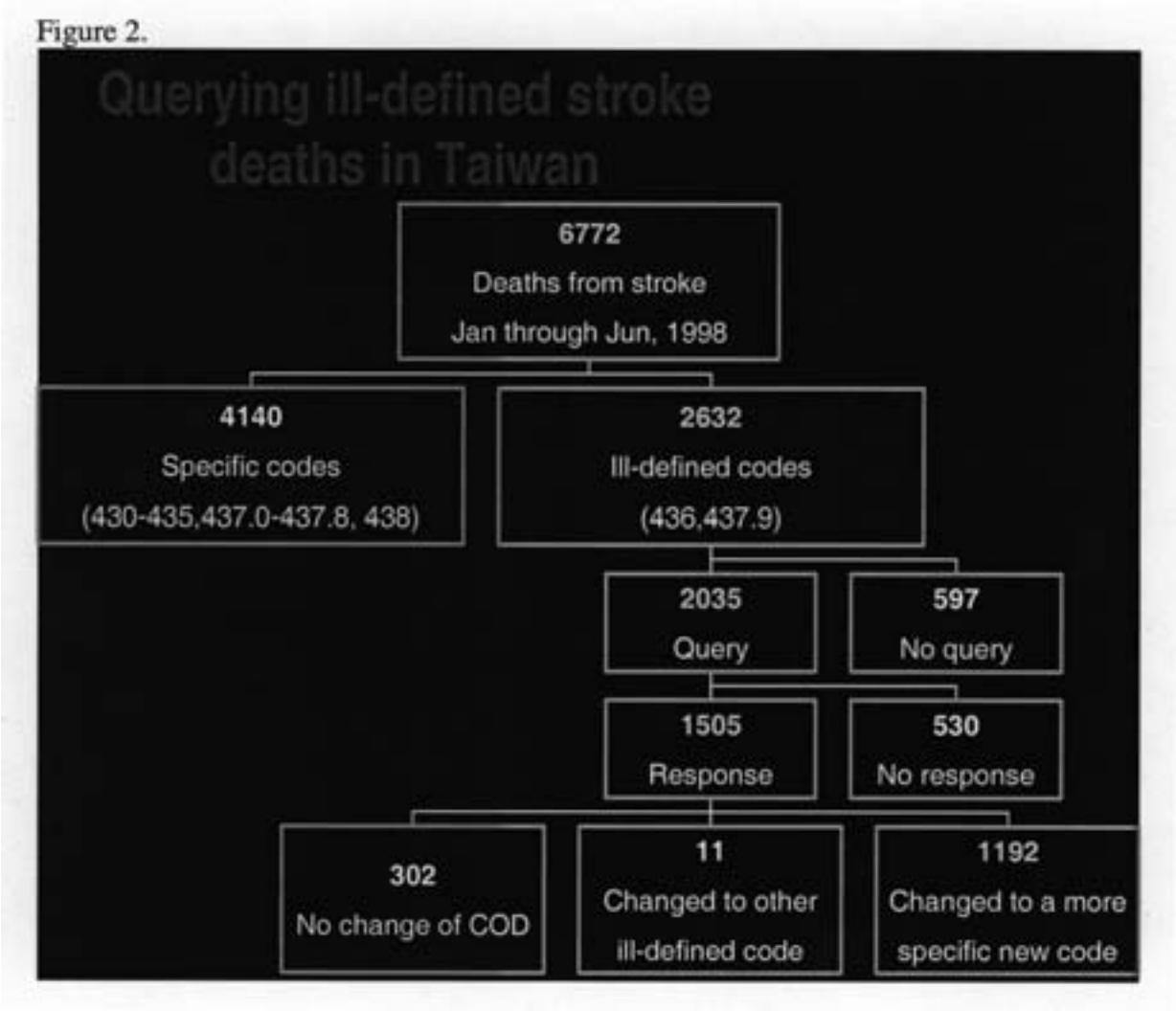
號之

證明書開具單位填寫				衛生單位註碼
(一)姓名		口性別 ①□男 ②□女	(二)國民身分證統一號碼	
戶籍所在地	省(市) 縣(市) 鄉鎮(市區) 村(里) 街(路) 段 巷(弄) 號之			縣市 鄉鎮
(三)出生年月日時	民 前□ 後□ 年 月 日 上午□ 下午□ 時 分 (出生後未滿一星期死亡者需填寫時間)			年 月 日
(四)死亡年月日時	民國 年 月 日 上午□ 下午□ 時 分			年 月 日
(五)死亡地點及場所	省(市) 縣(市) 鄉鎮(市區) 村(里) 街(路) 段 巷(弄) 號之			
	①□醫院 ②□診所 ③□助產所 ④□自宅 ⑤□其它			
(六)死亡種類	①□病死或自然死 ②□意外死 ③□自殺 ④□他殺 ⑤□不詳			
(七)死亡者行職業	①□在何處工作從事何種行業	②擔任何種工作及職務		職業碼
(八)死亡者婚姻狀況	①□未婚 ②□已婚 ③□離婚 ④□配偶死亡 ⑤□不詳			
(九)死亡原因：(儘量不要填寫症狀或死亡當時的身體狀況：如心臟衰弱、身體衰弱)			發病至死亡之概略時間	原死因註碼
1.直接引起死亡之疾病或傷害： 甲、				
先行原因：(若有引起上述死因之疾病或傷害) 乙、(甲之原因)：				
丙、(乙之原因)：				
2.其他對於死亡有影響之疾病或身體狀況 (但與引起死亡之疾病或傷害無直接關係者)				
以上事實確屬無訛特此證明				診斷或證明者身分代表
醫師姓名及證書字號：				
醫院(診所)名稱及開業執照字號：				填表人蓋章
醫療院所代號：				
院所地址： 省(市) 縣(市) 鄉鎮(市區) 村(里) 街(路) 段 巷(弄) 號之				
中華民國 年 月 日				

註：死因時來如發現錯誤，惟錯誤係在當時難以避免情況下發生時，診斷者不負法律上之責任。 (紙張大小：A4)

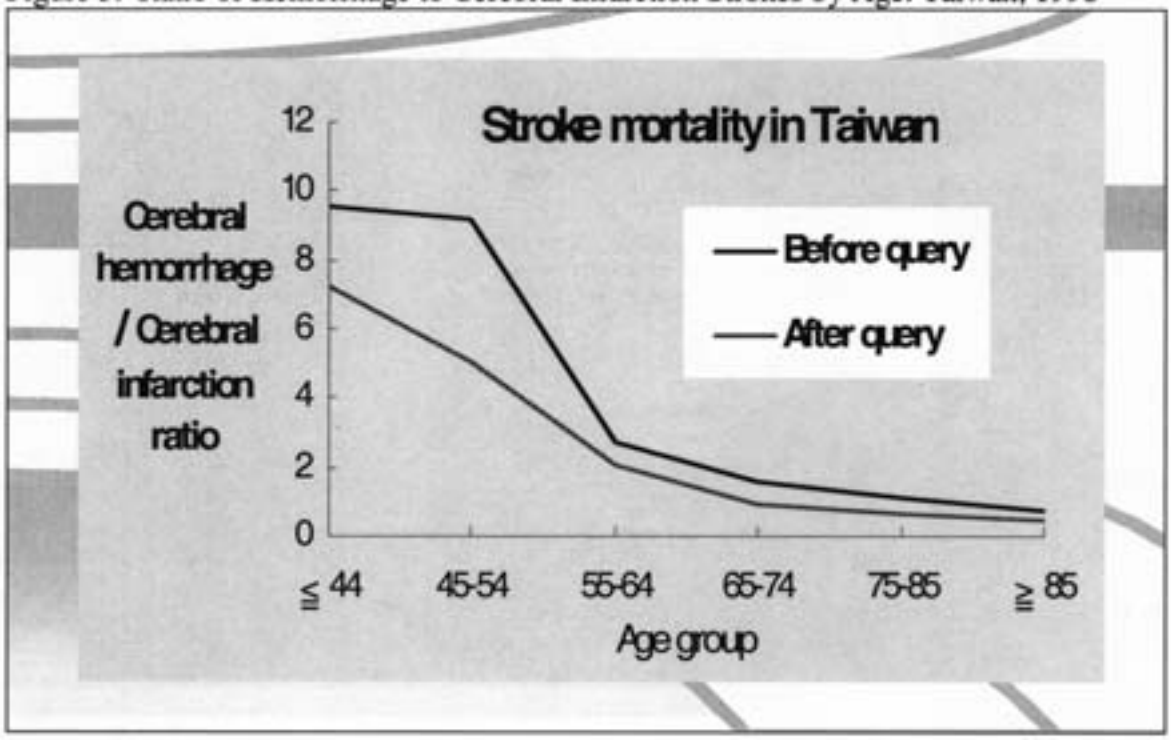
We also query cerebrovascular diseases because they are the number two killer in Taiwan. We have 6,000 deaths; some of them are very specific, and some of them are ill-defined, such as stroke. In Taiwan, in almost every hospital we have a CT scanner so we can diagnose the hemorrhage. We just specifically ask whether this stroke is a hemorrhage or infarction, so we can find a lot of change. Figure 2 shows the results of querying 2,632 ill-defined strokes out of a total of 6,772 stroke deaths.

Figure 2.



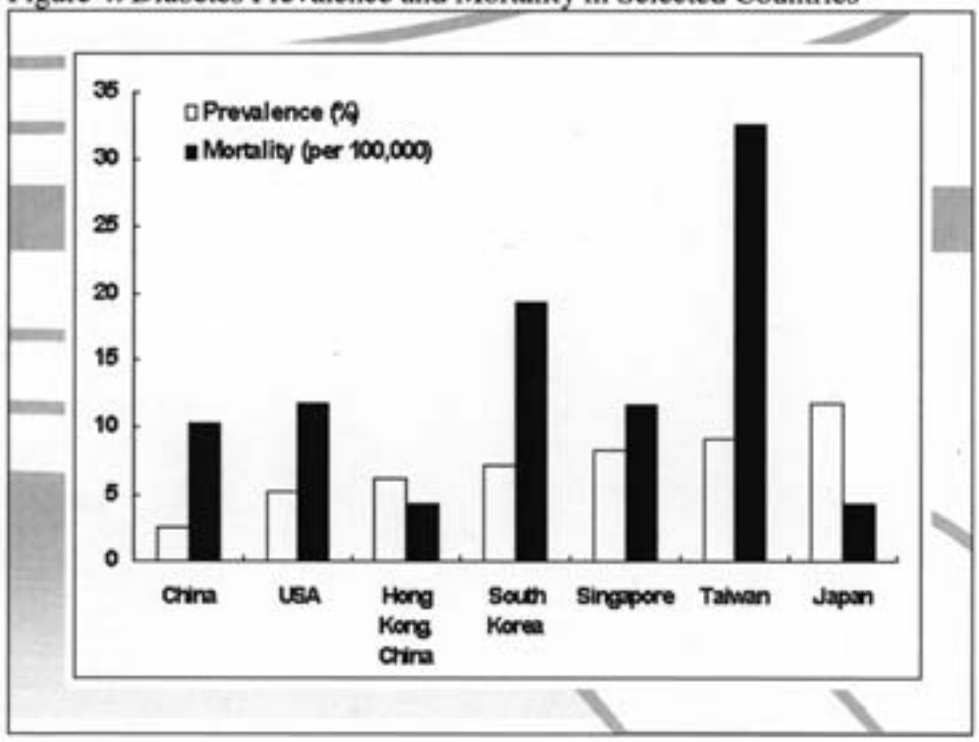
In Taiwan, as in Japan, we have a very high ratio of stroke with hemorrhage compared with infarction, unlike in Western countries (Figure 3). A lot of people use mortality data to show this rate. In one of the papers published in *Lancet*, the data show that something is wrong because many of the strokes are ill-defined. After querying the ill-defined responses, we find that the ratio decreases, especially for middle-aged people. We want to show that it is very important to have clarity.

Figure 3. Ratio of Hemorrhage to Cerebral Infarction Strokes by Age: Taiwan, 1998



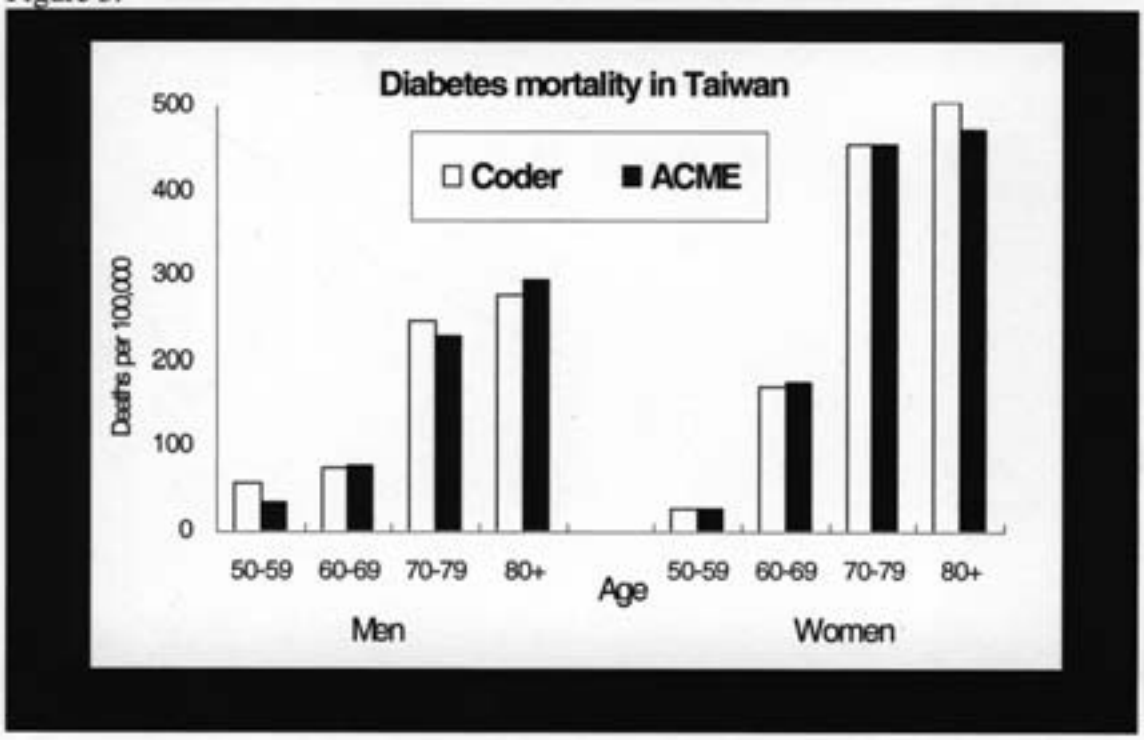
Another one of our findings is that average mortality for diabetes in Taiwan is very high compared with other Asian countries and with the U.S. (Figure 4). The white bars show the prevalence rates. Even though the prevalence rate in Taiwan is not very high, why is the mortality rate so high? We have three hypotheses. The first one (1) is that coders in Taiwan are more likely to code diabetes as the underlying cause of death than in other countries. The second one (2) is that certifiers in Taiwan prefer to put diabetes in Part I more than in other countries. The third hypothesis (3) is that we have poor care for diabetic patients, but I will leave that for another study.

Figure 4. Diabetes Prevalence and Mortality in Selected Countries



We obtained samples of the death certificates. We recoded all deaths mentioning diabetes using ACME. We found that the rates according to ACME and the original coder did not differ very much, which means that our coders are of very high quality (Figure 5). So I think the second hypothesis is the possible explanation because we just got data from Sweden, and we found that of those deaths that mention diabetes, an extremely high percentage had diabetes placed on Part I of the certificate. So I hope that, if other countries have a similar interest, we can have a cross-country comparison to see whether physicians prefer to put diabetes in Part I as opposed to Part II.

Figure 5.



My conclusion is that querying is very important and can improve the quality of cause-of-death statistics. Through cross-country comparison studies, we can pinpoint our own problems and can also answer some of the questions we cannot answer through the data of our own country.

Thank you very much.

Discussion on Session 8

L. GERAN: Eric [Jougla], you mentioned differences in coverage in your study. Could you comment, with regard to differences between countries reporting statistics on the country of residence versus the country where the death occurred, whether there is a possibility that some deaths in Europe are not being reported anywhere in the statistics?

E. JOUGLA: The situation about this is not good for European countries. For instance, for some countries where a resident dies abroad, the cause-of-death information does not come back to the country of residence. The idea at the level of Eurostat is to implement a system of exchange of information between countries. However, we are really at the beginning of this.

L.A. JOHANSSON: Yes, there is a possibility that a death is not registered anywhere, and there is also the possibility that the same death is registered in two countries. We do not know quite how big this problem is, but we certainly have to do something about it.

R. LAURENTI: I would like to ask Donna [Hoyert] and [Graham] Jackson whether there is a problem in the United States or Scotland that the person who does the query is not a physician? In our case, in Brazil, the physician that completes the death certificate does not like it and will not answer a query if it is not made by a physician from the Health Service.

G. JACKSON: The queries that we send out are sent with the signature of our medical advisor, who is a doctor. I think that does help the quality of the response that we get back. However, if they were sent with my signature, I do not think we should get such a good response.

D. HOYERT: Generally speaking, our query letters do not have the signature of a physician, and we think that is a limitation. If we had physicians available that could do the queries, we would prefer to do that.

L.A. JOHANSSON: I could perhaps add that in Sweden we changed our procedures about 10 years ago. The coders used to sign the letters, and they often got some very rude answers. But then we recruited a professor of internal medicine, or whatever, to sign them, and we got the most wonderful responses you could imagine.

C. ROONEY: It was really interesting to see the range of ways that people are trying to improve the quality of the data and trying to measure quality to get new ideas about things that we can each take back to our own countries and do. Going back to the previous question on the deaths of residents and non-residents, etc., the ICE on Injury sent a questionnaire to a lot of countries asking about which deaths they include and what they use as their denominator for their death rates. We found (it is published in the proceedings of the ICE on Injury) that the countries that use a population register as their denominator normally include in their numerator only the deaths of residents, that is, they exclude deaths of nonresidents, but they try to get all the deaths of people who are normally resident who die abroad. As you said, they had a problem getting the cause of death.

On the other hand, countries like England and Wales that use census denominators and demographic denominators calculated from that include in their numerators all the deaths that happened in the country, whether they are resident, nonresident, tourists, or anybody who happens to die in the country; however, they make no attempt to capture deaths of residents outside.

It does mean that there are certainly certain deaths that are counted twice and others that are never counted at all. A death of a Swedish resident in England in a road traffic accident would be counted in both countries. In contrast, a death of a British person in Sweden would not be counted anywhere. We do have some results, but we cannot quantify it. That is another step that we wanted to take in the future.

M. PACE: I would like to ask Donna [Hoyert] or Graham Jackson if you have any kind of information showing that the release of information on good certification practices or specific training programs and campaigns have ever influenced the amount of queries or the distribution of different cause-of-death queries? It is a bit complicated, I am afraid.

G. JACKSON: It is a very good question. I think the answer is that we do not have a sophisticated mechanism for measuring that sort of thing, but we do try to provide some information to assist the training schools, the medical schools, to give at least some positive training to the doctors on certification. I think you will find out as your project continues that they give very little time to that as part of the medical education. That is really the serious problem.

I mentioned that when we introduced a new version of our cause-of-death certificate to include the fourth line in Part I, we took that opportunity to improve some of the background notes. We did notice some small changes, specifically diabetes. Also, we found more mentions of multiple sclerosis, both of which were mentioned in the notes, so it meant that people were looking in the notes.

We also at that point produced a set of examples in a pack of overhead slides. We supplied packs of these to all of the medical schools, so that, in effect, they had a ready-made half-hour or 1-hour lecture that they could give to the students. That is something you would want to build on by having that sort of information available more locally and perhaps online and interactively.

D. HOYERT: Oregon and Washington State both have better tracking systems with their query programs than other states. They both note that when they introduce a new query, they see a change over time; the certifiers learn from these queries what they need to do to query less often. I guess that would be an example.

We did a study in which we added the fourth line and instructions at the same time. Since we have a decentralized system, the states picked and chose among the possibilities, so we had a variety of changes. Consequently, we were able to compare those that just had instructions, those that just added a line, those that did both, and those that did nothing. The biggest change in terms of diabetes seemed to be the addition of the fourth line. I realized after hearing a comment from France that I have seen on a U.K. video a study in which there was some related analysis of effectiveness. Maybe we will get Cleo Rooney's comment on that.

E. JOUGLA: Just to comment, what I feel about queries is that there is a very large gap between what you have presented on the situation in the United States and this very precise manual. In Europe, we would need at first to do something intermediate, something quite simple such as adding (preliminary) guidelines to query.

C. ROONEY: Paul Aylen did the video and piloted a certificate in a different format, which has the same lines and things but is laid out differently, with instructions that are color-coded to each section of the certificate. The study was not very big, and it did not really show that the format changes made much difference. So no, sorry, no evidence.

R. LU: You mentioned the methodology problem with the evaluation study because different sources have different purposes. For example, in the Norway study, you used the cancer registry, but that registry is for incidence, so how do you define? Some people have cancer but do not necessarily die from cancer because prostatic cancer can be cured after surgery. So in your study, how do you check whether they died from prostate cancer or not? Is there any information that you verify?

F. GJERTSEN: Yes, I agree with you; this is a problem. This is mainly one of the reasons for doing this study; we want to see if the routinely used information from this register affects quality. Are they using the

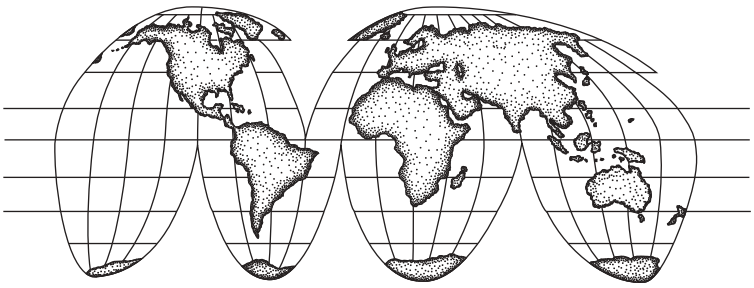
information because of the link between the two registers and not because they believe that these diseases have affected the course of that? So yes, we are very aware of that issue. It can be a problem, of course.

G. LEGALL: This is a question for Eric [Jougla]. In your comparisons, you said that it was based on persons over 64 years. Do you have any idea what may be happening in the older age groups?

E. JOUGLA: You mean considering the difference in mortality? The situation is quite different. For instance, what I show you appears in a very bad situation, and that is why I frequently focused my presentation about France on this problem. If we look to the mortality of those 65 years and older, the situation is quite reasonable for France. We are the best in Europe in terms of mortality for those 65 and over. We really have a problem with premature mortality. Then, to answer to your question, the figures are quite different for old age.

SESSION 9

Special Topics



Session 9: Special Topics

Dr. Cleone Rooney (moderator), Office of National Statistics, England and Wales

We are going to start this session with a presentation by Eric Jougla. He will tell you some interesting results from the study of Eurostat countries, including the difficulties associated with getting comparable data on important causes of death. Following his presentation will be a panel discussion.

The Quality of Suicide Mortality Data

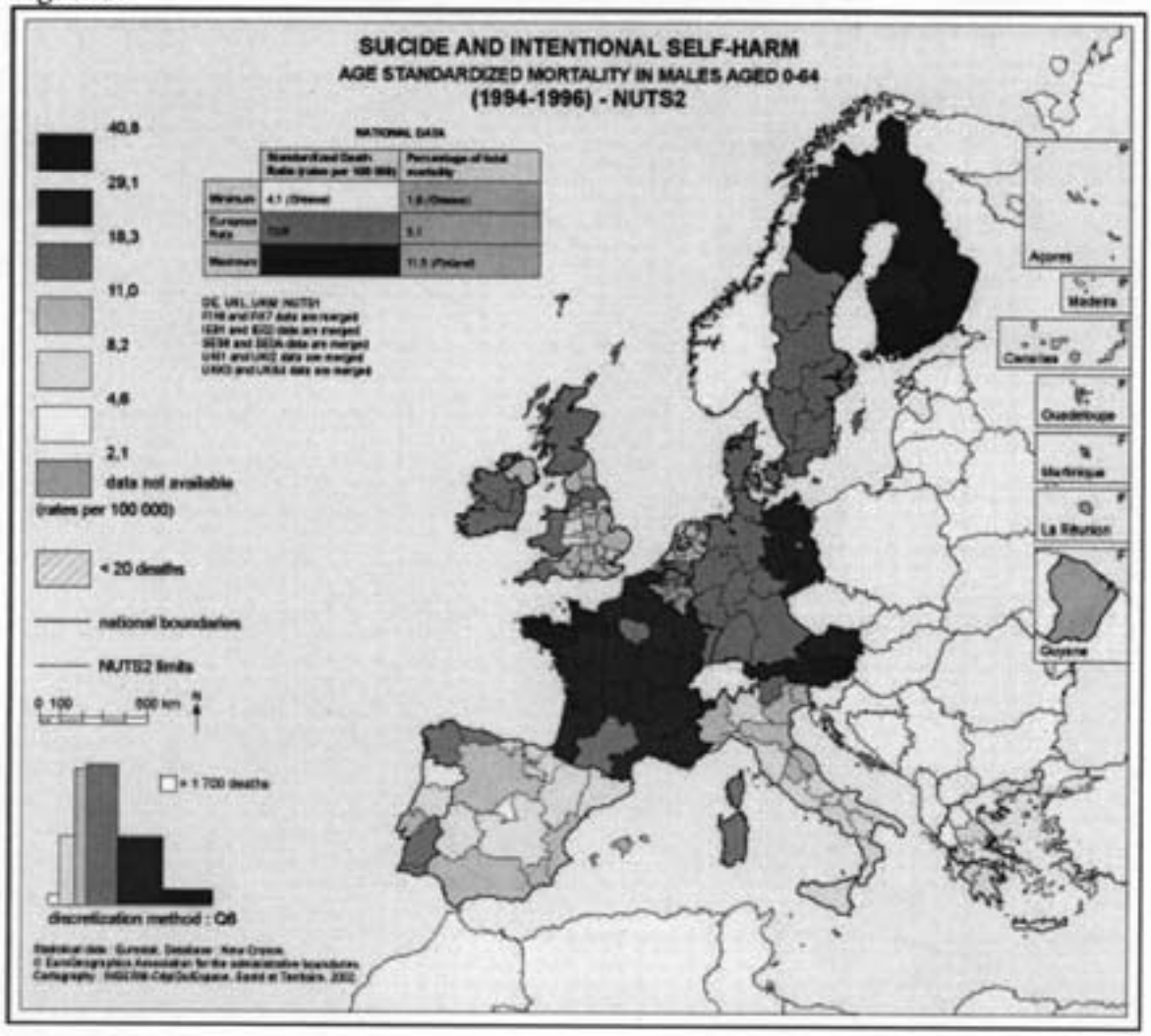
Eric Jougla, National Institute of Health and Medical Research (INSERM), France

A part of the work that I will present was presented by Gerard Pavillon at the last ICD WHO meeting. In many countries, suicide prevention is a public health priority. We have now in France a national action strategy that is aimed to promote suicide prevention, to reduce access to the means of suicide, to improve care after suicide attempts, and to improve epidemiological knowledge on suicide. In this last context, mortality data are frequently used as basic data. Mortality data allow us to outline some important epidemiological features of suicide in France, in particular, the high rates of suicide among adolescents and the poor situation of France concerning suicide mortality in comparison with other countries. This information has led to the selection of suicide as a public health priority in France.

I want to illustrate these two points. In France, we observed a total of 4,800 deaths by year between 15 and 24 years, and 15 percent of these deaths are due to suicide. That represents the second cause of death among adolescents.

Figure 1 shows a map of suicide rates in France in comparison with other countries. It concerns premature death, less than 65 years, for males. You can notice that mostly all the regions in France are in the highest category of mortality; in particular, the northwest region of France has very high suicide rates. Similarly high levels are seen in south of Finland, East Germany, and Austria.

Figure 1.



Potential sources of bias affecting these figures may be differences in medical certification and in medical codification between countries. Medical codification is not an important source of bias for suicide because when there is a mention of suicide on a death certificate, it is almost always selected as the underlying cause of death. The main problems can be found at the level of certification.

In this presentation, I tried to assess the French data for the sources of potential certification biases. I have two objectives. The first one (1) is to assess the level of underestimation of suicide based on the official data, and the second (2) is to assess the impact of this underestimation on the epidemiological characteristics of suicide. To analyze the effect of these potential biases, I focused on the concept of concurrent causes of death, which are causes of death that can hide suicide in the routine data.

In France, it is important to distinguish between two types of concurrent causes for suicide. The first is violent deaths of undetermined intent, for example, a declaration of a fall from a high place on the death certificate without indicating whether it was an accident or a suicide. The second concurrent cause concerns deaths with unknown cause. In France, the level of unknown causes constitutes an important problem. It is very often explained by a lack of feedback information to the Statistical Office on the cause of death after a legal inquiry.

For these two types of concurrent causes, we have some results from specifics inquiries. For instance, for events of undetermined intent, we have conducted a retrospective survey among certifiers based on a query on 500 cases of undetermined intent. From the results, we can assess that about 35 percent of this category are, in fact, suicide. For unknown cause, we have carried out specific surveys in some forensic institutes. These surveys are not representative of the situation in France as a whole, but they are important. From the results, we can estimate that 25 percent of the unknown causes of death in France are in fact suicide.

We have extrapolated these different results to the official data in France. For suicide among adolescents between 15 and 24 years, there were in France in 1998, 663 suicides in the routine statistics. At the same time we found 161 undetermined intent deaths, and a large number of unknown causes, 320. We can correct the suicide numbers by applying the 35 percent to 161 and the 25 percent to the 320. We obtain a total of 800 deaths by suicide.

That means that we can estimate the undercount of suicide from the official data in France at about 20 percent. If we applied the same correction method by sex, we obtain a similar underestimation of 20 percent for each sex. Thus, concerning our first objective, we can conclude that there is a large underestimation of suicide deaths in official statistics from France.

Let us apply this method to specific mortality indicators. In Table 1, I present trends in suicide rates in France over 10 years, between 1988 and 1998. There is a decreasing trend, more marked for women. Now we can apply the correction rate to all the years taking into account for each year the level of undetermined and unknown causes. The corrected figure obtained is very similar to the figure based on the official data with the same level of decrease.

Similarly, in Table 2, I show the level of the sex ratio for suicide. In France, the death rate by suicide for males is about three times higher than for females. This sex ratio does not change after correction.

Table 1.

Change of suicide rates between 1990 et 1998 (before and after correction)

Sex	Age	Suicides	"Corrected" suicides
Men	15-24 years	-9%	-11%
	<65 years	-7%	-7%
Women	15-24 years	-18%	-19%
	<65 years	-13%	-11%

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Table 2.

Suicide mortality ratio male / female (before and after correction)

Age	Years	Suicides	"Corrected" suicide
15-24 years	1990	3,2	3,2
	1998	3,6	3,5
<65 years	1990	2,8	2,8
	1998	3,0	2,9

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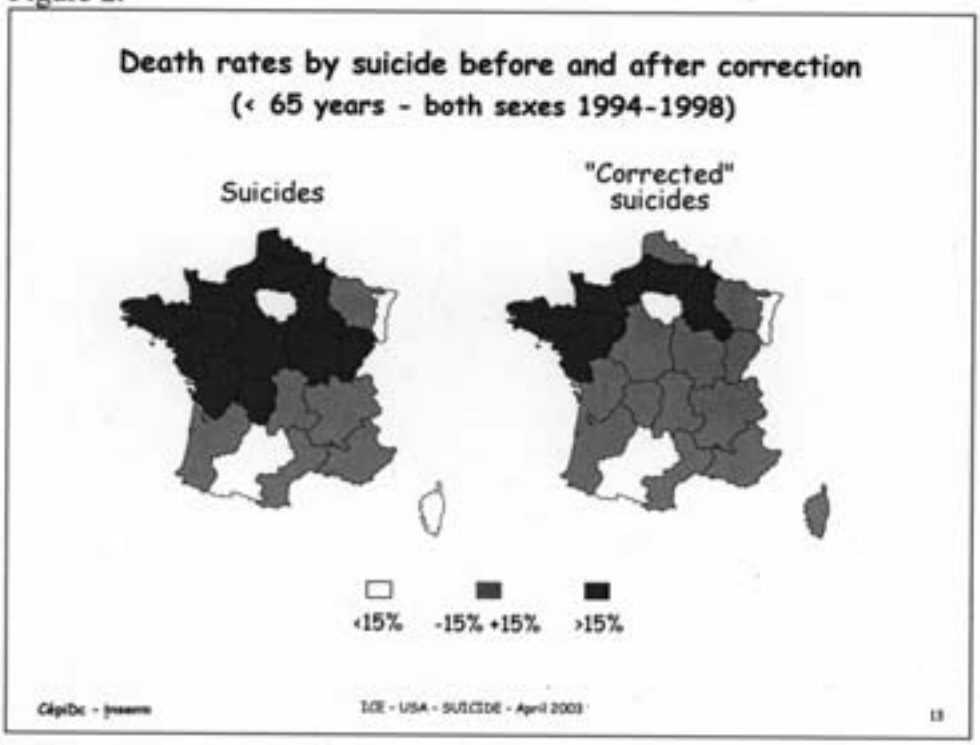
In Figure 2, I present variations in suicide rates among French regions. There are very marked gradients, in particular, high rates in all the northern areas, especially in the northwest of France. When we correct the numbers, using the same previous method, taking into account the level of undetermined and unknown causes in each region, we obtain very similar differences between regions.

Figure 2.



We used the French results on proportion of suicides in undetermined and unknown cause and applied them to the other countries. This exercise has been done by other authors with similar results. In Figure 3, the overall ranking of the different countries for suicide rates does not vary significantly after taking into account the concurrent deaths, except for Portugal. After correction, this country has high mortality suicide rates. This is explained by a very high level of undetermined events in Portugal.

Figure 3.

Then, concerning our second objective, we can conclude that the demographic, geographical characteristics, and time trends of suicide change slightly after correction of the official national numbers. This conclusion is quite important, and in the analysis of the impact of potential biases, I would like to distinguish between two different concepts. The first one (1) may be called validity or accuracy. It is linked to the exact number of suicides, and the previous results show that in France, for instance, the validity is not good. There is a large underestimation of suicide numbers in the routine data. The second concept (2) that we can call reliability covers the following question: are the existing biases stable by subcategories? In the case of France, we can conclude that there is a stability of the biases for the main epidemiological characteristics. This is an important conclusion because it means that when we report on sociodemographic characteristics, time trends, or geographical differences in suicide mortality on the basis of the official mortality data, the figures may be considered as sufficiently reliable.

One limit of the previous method for investigating the biases is that we considered only two types of concurrent causes: unknown and undetermined causes. There certainly exist other types of concurrent causes to take into account. Secondly, the proportion of suicides in the different concurrent causes is assumed to be steady in the extrapolations that have been presented.

Some general recommendations for improvement of the quality and comparability of suicide figures can be drawn from the literature, such as the need to define operational criteria to decide, after a violent death, whether it is a suicide or not. The U.S. has outlined such criteria. Other authors clamor for psychological autopsies to determine if a violent death is a suicide. The demand for a systematic item for suicide in the death certificate in case of violent death and the problem of the feedback of information after legal inquiry also remain important domains to address.

Thank you.

Discussion

C. ROONEY: Thank you very much, Eric. That was an excellent introduction to the problems that we all face in trying to get reliable and comparable statistics about important causes of death.

R. LU: First, in the interest of this study, will the sociologists' theory change after your corrections? Second, in the United States they developed an injury matrix. Sometimes, if you see the mechanism, it means that for some methods of death, it is easy to define the death as a suicide, but for some other methods it is very hard to define the intent of the death. So did you ever try to separate your injury into different methods of death? For example, some deaths like those from shotguns are very easy to decide if it is a suicide. In Taiwan, hanging is a very common method of suicide, but for poisoning it is very difficult to ascertain whether it is accidental or a suicide. Drowning is also very difficult. So maybe in these kinds of suicide we should verify, but for other methods of suicide there is not a problem.

C. ROONEY: Sorry, but I think part of the problem may be not getting the information on the method, either. You are not getting any information at all on how the death happened. It is not just that you are not getting the verdict, the manner of death, is it?

E. JOUGLA: I think there is also a problem of coding in this field. For instance, we notice that there are not real rules for the examples of hanging without specification of suicide or accident. In some countries we code suicide. I think in France, if we have hanging without any other specific information, we code suicide. That is not the case everywhere. That is why your remark is important, because it depends on mode of suicide.

R. BECKER: We all know that for many reasons, such as religious, legal, or cultural reasons, suicide may not appear on the death certificate and on the record. Is there any study about the big difference we saw in the data that one or more of these factors can be influencing?

E. JOUGLA: We tried to approach the problem in a Eurostat report. That is a large problem. I think studies about the quality of suicide data are among the most frequent of quality-of-cause-of-death studies. While there are a lot of studies of this kind, they are difficult to carry out. We have learned, for example, that for Europe, religion has an impact on the confidentiality rules in some of the countries. In France, we have large confidentiality considerations for our data. At the same time, a physician without inquiry can determine a suicide. It is not absolutely the case in England, for instance, where you can have a verdict of suicide only after a legal inquiry.

C. ROONEY: We can also only have a verdict of undetermined after a legal inquiry. I think there are enormous cultural and legal differences that make suicide data difficult to make comparable. I was actually surprised to find through the Injury ICE and some work that we did with our own data that homicide data equally is not comparable at all across countries. And certainly what gets into the vital statistics in some countries is only quite a small fraction of their real homicides, which includes England and Wales up to a point, so we have to do estimates.

F. GJERTSEN: What I have learned from this is that the quality of the suicide statistics is really adequate for doing the French analysis. It was really interesting that you mentioned 20 percent underestimation because in Norway in 1980, we did an evaluation of the coding routines we have, and we tried to measure the effects of the additional information. We increased the suicide figures by 20 percent because of the routine inquiries back to the physician. So that is very interesting; it is already included in the official statistics.

C. ROONEY: I think it is always interesting to know the efforts that people are making to try and improve these statistics, or to try and make better estimates. As a minimum, in England and Wales, when we are

analyzing suicide trends and patterns, we include all the undetermined intent injury and poisoning deaths because we have reasonable evidence, going back a fairly long way, that the majority of them are cases where the coroner will not give a suicide verdict. This is because the coroners tell us that they have to have the same standard of proof that you would have for a homicide, that is, that the persons did not just intend to harm themselves, but intended to die.

My favorite example of not being able to get this is a case that was in the newspaper where a woman had left 20 suicide notes, phoned her ex-husband and phoned her sister to say she was going to kill herself, taken a bottle of antidepressants, a bottle of sleeping tablets, a bottle of brandy, and drowned herself in the swimming pool. There was an open verdict. The intent could not be determined because she was under the influence of drugs and alcohol and might have accidentally slipped into the pool. So it can be very difficult to get these deaths reported as suicide.

Special Topics: Problems in Mortality Statistics, ICD Coding and Automation
Panel Discussion—Cleo Rooney, Lars Age Johansson, Harry Rosenberg, Donna Glenn, and Gerard Pavillon

C. ROONEY: I am going to tell you very quickly what you told me on the questionnaires I distributed earlier and then move on to the panel and get them to give us the benefit of their experience in how to address these problems that we all face. These are very basic things that I looked at in the questionnaire.

Following from Eric Jougla's presentation, almost two-thirds of all the people who filled in the questionnaire said they have trouble getting deaths from accidents and violence coded properly. Half have trouble with poisonings, almost three-quarters with postoperative deaths, and almost half with medical and surgical errors. This is actually the coding question, and we will talk a bit more about how we code these manually and in the automated system and what future changes there might be to make the coding easier when you have actually got the information.

We also asked what made it difficult to produce good statistics, and is anyone surprised what came out on top? I suppose I was surprised that almost half of people did not think they had a problem with bad certification, that it was not an important problem for them in producing reliable statistics. Bad certification by doctors comes out on top, a long way above anything else. Bad certification by coroners, medical examiners, etc., was also a problem, and a few people particularly mentioned specific types of people other than doctors that I had not included in my list.

Almost 30 percent of people had trouble with incomplete registration of cause of death. That I think is one that we ought to be able to tackle in a variety of ways. Obviously, some countries have real problems with deaths being able to be registered without any cause at all, but we can try and move on from that. When you only have an incomplete cause, we can try and follow it up with querying.

Perinatal Certificates

C. ROONEY: I also asked how many people used the perinatal certificate, and I was surprised; quite a number of countries said that they do use the special WHO perinatal certificate. I really thought it was only a very small number. What surprised me even more is that they use that certificate, that is, they manage to include all those deaths by cause in their infant mortality. How do you get a single cause from that certificate? I can show you later how we do it.

G. PAVILLON: I have a part of the answer for France. We were aware of your experience, and when designing the neonatal death certificate, we included a sequence and asked for the underlying cause of death.

C. ROONEY: Thank you. So you actually have a better certificate. It is not really exactly what is recommended by the WHO.

G. PAVILLON: No, it is not the WHO recommended format. It looks like it.

C. ROONEY: It looks like it, but it is better.

R. BECKER: We have 48 countries and territories in the Americas. Three of them have a specific perinatal death certificate, all different with different ages to be considered, and different rules.

C. ROONEY: This is the perinatal certificate. The problems that we have had with it are that basically, if you use the certificate as it is recommended, there is no way to select an underlying cause of death. There is no sequence there. You cannot get back to what started it off, so we also have additional instructions in that

our certificate actually says main causes, main fetal causes, main maternal causes with an ''S'' on the end. They write four or five things on that line, and we cannot do anything at all with it. They write anything in Line E, so we have actually come up with a way that we classify it. Are there any countries here that genuinely use the WHO certificate? Do you include the deaths by cause in your infant mortality, and if so, how?

R. CASEY: We just have a question, main contributing cause, so we conveniently left the ''S'' off the question.

C. ROONEY: But do you pick the maternal or the fetal?

R. CASEY: Fetal.

C. ROONEY: I am told that you sometimes just take the first mentioned on the whole certificate, whichever line it is on, and that is it.

Improving Medical Death Certification

C. ROONEY Forty percent of the respondents said that less than 1 percent of their deaths were tabulated as unknown cause. We saw what a good figure Scotland was able to get. Twenty-seven percent said 1 to 5 percent; 27 percent, 5 to 10 percent; 7 percent said between 10 and 20 percent were unknown cause; and nobody who answered had more than 20 percent of their deaths assigned as unknown cause. So that is something. I have asked this question before and got worse results than that.

The first question to address is how we can improve the quality of death certification because that is the biggest problem people are complaining about. I would like to hear from each of the people on the panel. I shall let the Americans field one response, if they would like.

H. ROSENBERG: I think this is an important question, and one with which we have a great deal of experience, and one that is actually amenable to a number of actions. In 1989 and in 1991, we held national workshops in the United States to look at this and come up with some suggestions for improvement. Some of the improvements will require what I would call buy-in from key stakeholders. That sounds like a lot of bureaucratic gibberish, but what that means is that to really effect a major change in a country as diverse and large as the United States, for example, you have to get a lot of people involved in the solution to the problem. That includes the professional associations.

In the United States, for example, the American Medical Association (AMA) has to put improving cause-of-death certification on its list of priorities because they can actually influence physician practice. We are happy to say that within the past 2 or 3 years, the AMA passed a resolution that gave prominence to the importance of medical certification of death as a physician responsibility.

So I think, first of all, that you have to do some political fertilization to hopefully reap the reward of a healthy fruit, which would be better medical certification of death. There are many ways of persuading the medical community that this is an issue worth addressing and of raising their level of consciousness.

In the workshops, one of the very simple recommendations that we tried to implement was the following: many people who are epidemiologists, statisticians, and physicians do not realize that the statistics that are the basis for health planning and budgeting are from the information that they put on the death certificate. They do not make any connection between completing this form and national health data. So the recommendation was made that in any article on mortality statistics and in any publication, in a prominent place, the author(s) should say that the source of these data are the physicians' statements of cause of death on the death certificate. In this way, the message comes home.

We have been trying to do that. In the news releases for our annual reports on vital statistics, the last paragraph always states that the source of this information is medical certifiers', physicians', coroners', or medical examiners' statements on the cause of death on the death certificate. We are trying to build that connection.

Another thing that we believe can be very helpful, and I believe Scotland and others have found this to be the case, is that the instructions on the death certificate have examples of properly completed death certificates. A picture is worth a thousand words. If they see a causal sequence in Part I and other significant conditions in Part II, they can say, ''Ah-ha, I never understood it before, but I do now.'' In fact, when we introduced the examples on the standard U.S. death certificate for the first time in 50 years (it was in 1989), we got telephone calls saying, ''Thank you, we never knew how to complete the death certificate but now we understand.'' So something as simple as better instructions with examples of completed certificates can be effective.

There are many, many practical avenues to improve certification. One of the workable suggestions is Continuing Medical Education (CME) credits When we conducted a course 3 weeks ago, I believe, in Hungary on mortality statistics, we had a 1 and a half hour seminar on improving cause-of-death reporting on the death certificates. The physicians in the audience made the suggestion that CME credits would be a very effective way of reaching physicians who are already in medical practice.

Another way is during the mandatory physician recertification process, which I think is every 5 years in Hungary, that there be a requirement that people be trained in completing the death certificate. What I am trying saying, in summary, is that there are a multiplicity of approaches, very practical, not necessarily difficult to implement, by which we can reach physicians.

One of the most important things—and this goes back to Graham Jackson's presentation—is querying. A good querying program can have an enormous educational benefit. It is the way, number one, that physicians realize that somebody is looking at the death certificate and number two, it is an excellent opportunity to instruct and help train the physicians who help complete the death certificate. Querying can be extremely effective.

The other question that was raised was whether or not there are positive incentives. Someone said we should pay physicians to complete cause-of-death statements and to improve the quality. I do not agree. I think that this should be a part of good medical practice. I am not so cynical to think that physicians do not want to do the best job possible. I think that if they can learn how to do it, they will try to do a good job. Ultimately, the electronic death registration system may help, but I do not think it is a complete panacea.

L.A. JOHANSSON: We tried some years ago to get access to the training of physicians in Sweden, and we discovered that they have all in all 2 hours for all kinds of certification, which includes certification for insurance purposes, for sick leave, sick retirement, and whatsoever, and apparently certification for somebody who is already dead gets a fairly low priority. We have not been able to change the universities' attitude on that. What we have focused on in Sweden is to try and make the death certificate form as clear and as self-instructing as possible. We are trying to have enough space to have as clear instructions on the front page as possible; nobody would turn over the paper and read what is on the back. We have introduced a set of arrows to try to hammer in the idea that they are talking about a sequence of events and in which direction the sequence should go.

We made some comparisons of data before we introduced this new improved form and after, and we did get far better results. I agree with Harry [Rosenberg] that querying is extremely important. It has happened that doctors have called me and said, ''Thank you for sending a query; I am so happy that somebody reads what I have been writing.'' So in our setting where it is very difficult to interest physicians in training, I think that the design of the death certificate form is the most important factor.

G. PAVILLON: Yes, I too agree with what Harry and Lars [Age Johansson] said. I remember that in 1996 when we were thinking about the new form of the death certificate in France, we had a survey comparing two samples of physicians, one sample with a leaflet looking like the U.S. leaflet exactly, and another sample with just examples as Harry mentioned. We had 10 clinical cases and it appears that there was no difference in the quality of certification in either sample. That was the same exactly. So we chose to put examples on the new death certificates; it is easier. I think that many physicians are happy with that.

Now, I was a bit surprised about the percentage of people mentioning bad certification of causes of death by doctors. This is typically for me an opinion of physicians. My experience is that in France where they are coming in exactly the same, to have a look at the death certificates for such and such disease. For instance, last week a young physician came to have a look at death certificates mentioning systemic disease. He said, ''We do not know much about the death certificate; it is just something doctors rapidly fill in during the night, and it is not very good,'' and so on. After an afternoon, he was surprised. He had to look at 500 death certificates, and he was surprised. He said, ''This is exactly what I was expecting from the death certificates. The diseases I am looking for are always at a good place in the death certificates.''

So I think that, of course, we can say that we have bad statistics because most of the physicians are not filling out the death certificates well. However, I am not sure it is true. It must be true for some of them, but in many cases, I think two-thirds of the death certificates are quite well completed according to the conditions that are reported. There is place for improvement, I am sure, of course, but I do not think it is the main problem compared to the other problem of bad certification of cause of death by coroners or the forensic institute. Maybe this is a specific problem for France, but this one is really a problem for us.

Another aspect with which there are many possibilities, even if it is not very easy, is electronic death certification. It is not just because for me, and Eric [Jougla] agreed while we were talking very often of this possibility; we think of the future. We will be obliged to have electronic death certification in the near future. I think that it is a possibility to increase quality with interactivity, but it must not be forced into implementation. It must provide the possibility of interactivity. If the physician needs some additional information, the system should be designed so that s/he can interactively get this information. We will need a lot of experience and a lot of sharing experience at the international level, but maybe there is a very important possibility of increasing data quality at this level.

R. BECKER: On Monday, I briefly mentioned several factors that can influence the final results of any mortality analysis. One of these truly is the certification. We are making a very big effort in the area of coding and ICD and things like that, and I think we should have the same effort in this area, maybe creating a specific committee on our ICD network.

The physicians usually do not like to complete death certificates. Why? There are many reasons I can see. The first (1) was partially mentioned by Harry, namely, that they do not understand well the purpose. Training should include very strong discussion about the use of data. The second reason (2) is the nature of the profession. ''I am a doctor; I am here to save lives, not to say that my patient died, maybe with my help.''

I have two more comments. When we have to train physicians to complete death certificates, usually it is being done in the course of medicine, but in an inadequate form and time. I think that we should train just before they are starting to complete death certificates, not at the beginning of the course. In many, many situations, countries and hospitals, those who are completing death certificates are just the new physicians coming to the hospital, residents and so on. So we have to work on these people, maybe with specific training just before the graduation.

One of the things mentioned was whether we can make it illegal to register a death without an adequate medical cause. I am afraid of that because it might result in getting more infarctions and strokes instead of senility and cardiac arrests. Also, queries are absolutely important, I agree, but we have to be very careful how to do that to avoid a situation where the re-completed or amended death certificate becomes an artifact, something created by the physician.

L. CHRISTENSEN: Hello, I am Lila Christensen from Denmark. I will just say that in Denmark, it already is illegal not to fill out the certification properly, but nevertheless some do not do it very well, and they are paid in advance for doing it. Still they want more money when we ask them to do it correctly. But we have no punishment if they do not do the work properly. I do not know what to do.

L. GERAN: A couple of very provocative comments were bringing things to my mind how we get depressed about all these things that are wrong with our data. But I look at certificate after certificate of suicides, for example, and I think, ''Oh, they are all certified wrong,'' or ''There is something wrong here.''

But then I forget about the 200,000 other deaths that I have not looked at and that were coded automatically and selected automatically, so you have to keep that in mind all the time when you are looking at exceptions.

The other thing was, in terms of physician education, I am trying to put this into a larger context of how doctors are trained. In Canada, and I think internationally over the last 50 years, there has been a huge decrease in the number of autopsies that are being performed. I think there is this feeling by doctors that they do not need to worry about cause of death or get their hands dirty inside a body because science has told them all this stuff.

In Canada, autopsy rates have gone from about 50 percent in the 1950s to about 10 percent nowadays. So I think in those broader practices of medical education and scientific advance, you have to keep that in mind when trying to train the physicians to certify better because overall, they are less and less concerned about death and autopsy and all that. They are more interested in the more cutting-edge things.

One of those things is electronic certification. We have a coroner in Southern Ontario who is trying to do an electronic coroner's report and get a coroner's database together. He wants to put queries into the line items Part I and Part II, so what he has done is put in ''pick lists.'' We are trying to discourage him very much from putting into the program a ''pick list'' because his information is being fed to the registrar and the registrar is coding it and sending the results to us. I will be very interested to know about this interactivity as it progresses in the future, about how we can query physicians, but not go down that road of having pick lists.

E. JOUGLA: It is a specific question about tables that you have shown about the medical and surgical errors. We have an increase in this type of data. I want to ask the experts their opinion about the place of medical and surgical errors in comparison with the disease that motivated the hospitalization. That could be a very bad disease. This question is posed at several levels: what must we do at the level of certification and at the level of codification and selection of the underlying cause of death?

C. ROONEY: I think they are very difficult deaths to code. I think they also are almost certainly under-reported on death certificates; the information just is not included a large proportion of the time. I think that it is actually relatively rare to be able to tell from a death certificate whether the death would have happened anyway because the person already had a lethal disease or whether it really was the case that it was largely due to something that went wrong in treatment. It is also very hard to distinguish between something that went wrong and just one of those things, one of those adverse reactions that some people have to a particular drug or treatment.

So to be perfectly honest, I do not think that this is information that you can get reliably from reading death certificate data. Other countries may disagree.

L.A. JOHANSSON: When I made my comparison of hospital discharge data and causes of death, our deaths due to misadventures in medical care went up by about 1,000 percent. I still think that is underreported.

Now, of course, if we are to obey the ICD selection rules, we would always select the disease that was the cause of the treatment as the underlying cause, which means that you would need multiple causes to capture this. We tried to evaluate this some time ago, and we very soon reached the conclusion that we need some special mechanism of dealing with misadventures in medical care. It is not just misadventures. It could be that the patient did not arrive in time, that some laboratory things went wrong or were sent to the wrong place.

Returning to the quality of certification, I would like to add that I do not think we should blame everything on the doctors. If you read the hospital records, very often we understand that it was difficult to certify the deaths because the patient had a lot of different, apparently independent diseases that occurred in no order whatsoever, and it is simply impossible to see any logical structure in it.

I think we should remember that the death certificate was designed, I think it was in the 1820s originally, to capture what we would today regard as avoidable deaths. It was never intended to capture deaths at a high age, where people had 55 diseases and you simply cannot distinguish among them.

Confidentiality of the Medical Certification

C. ROONEY: The next issue here is actually a fairly specific one that a few people brought up. It is the question of whether you get worse information on the death certificate if cause-of-death information is widely available to people other than the patient's family or those with a direct interest, particularly for stigmatizing illnesses that the family might not want people to know about, or is it actually a chance for the family and others to correct it, and make sure you get the right sort of cause?

H. ROSENBERG: I can comment on it briefly. In the United States, we have a decentralized vital statistics system, and I think probably about half the States have ''closed'' systems, where it is extremely difficult to get vital records information on cause of death.

Others have an ''open'' system. In an open system you can walk into the registration office and say, ''I am doing genealogical research, and I would like to look at the vital records.'' You could then peruse any vital records, including the cause-of-death information.

New York City is the one exception. In New York City, even the family cannot find out the medical certification of death. Their official death certificate does not include cause of death. That practice was instituted in the 1920s in order to improve medical certification, with the thought that if the physician knew the information was confidential, they would be much more forthcoming and candid in providing accurate cause-of-death information.

We did a study a few years ago in which we compared the information in States that have closed systems with that in States that have open systems. We found no significant difference in the information. When we tried to understand why, we inferred that physicians do not know about the legal framework within which they are completing the death certificates. They simply do not know whether the information is confidential or nonconfidential, and we did not feel that it really made a lot of difference. That is the U.S. experience.

C. ROONEY: Does anyone want to add to that? We have a little bit of evidence that doctors are unwilling to write stigmatizing things. Early in the AIDS epidemic, a lot of doctors used to write a certificate that just said pneumonia. They checked the part that said further information might be available later. When we wrote to them, then they told us it was AIDS.

What they tell us after the original certificate is confidential; what they write on the original certificate, other people can see. There is not very strong evidence. Confidentiality seems to have worked from time to time in England for a variety of different diseases.

G. PAVILLON: Cleo [Rooney], I remember now our discussion during the project on quality and comparability of data in Europe. Since then, I think that, for instance, we have very different systems in the U.K. and France. In the U.K., the death certificate is roughly equivalent but in France, it is confidential. I think that we have two types of systems, each adapted to the particular country. If the U.K. were moving toward confidentiality as in France, it would not work, and the reverse is true. We could not afford public death certificates. I think this is because of differences in culture between the two cultures.

Coding

C. ROONEY: n Volume 1, there are instructions at the beginning of the block of codes for AIDS and HIV about using just three-character coding and single-condition coding. Lars [Age Johansson], could you tell us a bit about what the Mortality Reference Group (MRG) said?

L.A. JOHANSSON: The MRG could see no reason why we should not use the fourth character. The suggestion from the group is to delete that note from Volume 1.

C. ROONEY: Some of the participants thought that we sometimes ended up with a mode of dying or mechanism of death, cardiac arrest or heart failure or something, as the underlying cause because the certificate had been badly filled in and you could not select something else as the cause of that particular mode of dying.

Now, Donna [Glenn] was going to talk to us a bit about how the acceptable sequences and selection rules work. I think in many cases, you actually can use the rules to get around mode of dying. You can ignore trivial conditions, you can make linkages, or you can use Rule Three.

The two examples that were actually given are ones where both things are written on the same line: 1) uremia and diabetes on line one, and 2) heart failure and liver cancer. These are pretty difficult to deal with, I think.

D. GLENN: First of all, with ACME, you have to understand that we in the U.S. are called ''literalist'' in our approach. We do exactly what the rules say and exactly what is in the ICD. We do not add and we do not subtract, and that bothers a lot of people.

I have examples of other cases where we did mode of dying. One thing that we did in the MRG that helped is that we expanded the ill-defined to include some additional conditions. I do remember heart failure, pulmonary, and cardiac arrest.

One of the examples here would be applied and taken care of if you are using the most current form of ACME. The other example that I see here deals specifically with diabetes. Diabetes is one of those diseases for which everyone has a different opinion on what to link it to. To make ACME work under our restraints, if the Index has a disease indexed as diabetic, we will do a linkage, that is, we will direct sequel to the diabetes. If it is not, we do not use linkage, and that has caused a lot of people concern.

So in the MRG, we actually are looking into the question of diabetes and whether to use more expanded diseases for direct sequels. We should have the results of that fairly soon since I have promised to run it. Then you have to understand, with ACME particularly, that the Decision Tables are done once a year. We are very adamant that we do not change ACME tables in the middle of the year. If we do, and we did it in 1999, we must rerun every bit of data that comes through the United States, and that is about 2.5 million deaths. So we do not do it.

Any changes to the Decision Tables for ACME must be finalized by the end of September, because our tables go to printers in October. Once they have gone to the printers, that is it for the following year. We are working with the MRG to get all the input from the international community we can, so that we can change these tables and have them meet the needs of everyone. However, they are done on only an annual basis, and we have the end of September cutoff.

L.A. JOHANSSON: I would like to say that what you regard as a mode of dying is far from self-evident. It differs from country to country. They are absolutely difficult. For example, heart failure could be a mode of dying; however, it could also be a condition you have been living with for years and years.

When I started working as a coder for Statistics Sweden, we very much tried to get rid of what we felt were modes of dying, so we would never accept heart failure as an underlying cause. We would never accept uremia as the underlying cause; we would look for something more exciting in Part II.

Then a few years later, we made an evaluation. We asked for hospital records and tried to evaluate the records to see what they really died from. We discovered that when we tried to assess the death certificate and pinpoint the most important condition, we got even worse results than if we had stayed with the mode of dying. That was because the death certificates very often leave out very important information. So we decided that we would not change this. We would become, if not literalists, more literalistic than we had been before, and if somebody does not like our data, well, that is the doctor's fault, not ours.

The Mortality Forum

L.A. JOHANSSON: Anybody can join the Mortality Forum. If you are not already members, please send me your address, and I will add you to the Forum. You have my e-mail address in the list of participants. It is almost correct. There will be an updated version soon, I suppose.

The Mortality Forum, to get on to the next bullet point, is not the forum where we make decisions on coding. Rather, we discuss coding and we try to map what differences we have between the countries. This has to do with the way the Mortality Forum is composed, that anybody can volunteer to join the Forum. It has no democratic representability.

To address the problem that we quite often code in different ways, the WHO and the Center Heads in 1988 set up the Mortality Reference Group (MRG). The MRG has the authority and the mandate to resolve these questions. Now, unfortunately we have lots of questions to deal with. I think we had about 200 questions or something on our waiting list, and it takes some time to resolve all these questions. We have worked quite hard. Last week, people called me a slave driver, and I do not know what, but we are now almost finished with our waiting list.

We cannot publish the results as yet because we need formal approval from the Center Heads, which we hopefully will get in October of this year. As soon as we have that, we will certainly try to make those decisions available through some Internet link, and I could also distribute them through the Mortality Forum.

Finally, I think the Mortality Forum would be a very good place to discuss national coding instructions, so if there is something that you feel other countries might perhaps take another view on, please submit it to the Forum and let us have a discussion on it.

Coding SARS Deaths

C. ROONEY: Now, SARS was a very hot topic just before I left England two weeks ago, not that we have had anyone who died of it. In fact, when I left we had not had anyone who definitely had it. However, it is clear that this is a condition that we need to be able to track. We are going to have to be able to tell how many cases have been admitted to hospital, how many cases have been notified, and how many people have died.

When ICD–10 was being developed and when the updating process was being planned, this is one of the things for which it was decided that we would keep the whole of the chapter beginning with the letter ‘‘U’’ empty. The second half of that chapter, codes U–50 to U–99, was supposed to be for anybody to use for what they liked; any country, any researcher, whatever, could use those codes, and they had no international significance. The U–00 to U–49 codes were supposed to be for new conditions that might be put there temporarily and then found to belong in a particular chapter or place, or else put there permanently, if they really did not belong anywhere else.

I think that the first half of the U block is actually supposed to be used by international consensus, but it has not quite worked that way. I thought this was the first disease to which we needed to award a new code. Again, it was discussed in the MRG, but I think there have been other discussions, with e-mails going all around the world and contributions from lots of people.

Has anybody actually decided nationally that they are going to use a particular code for this? Some people say it is a type of pneumonia of unknown cause, and thus it should be coded to J–18.8 or 19.8 or something. I find that to be problematic; I think it is going to be very difficult to find those cases again and to count them. You will have lots of unspecified pneumonias, and you would have to go back to the original text or something; if you do not have that stored electronically, then it could be very time consuming.

M. KIMURA: My name is Kimura, from Japan. I think our country decided to use ‘‘J’’ code as pneumonia, classified, anyway. The reason why we picked that code is that if we decided to use a new code, we would

have to change the law. This is extremely difficult for us. Therefore, we decided to use the old code. However, for future reference, we may decide to remove it to report as an official ICD–10 code. This is the only thing we can do.

L. GERAN: In Canada, as of Saturday, we had, I think, 8 SARS deaths out of over 150 cases. Certainly in the last polling that was done, it is now one of the greatest fears of Canadians, so we were very anxious for the Mortality Forum and the Mortality Reference Group to come to some sort of decision.

It is my opinion that this is a really good disease for the process of updating to test our system. Weekly, I got the United Nations update on mortality and morbidity, and Dick Thompson of the World Health Organization was inviting everyone to help out on this and that and the other thing for finding the cause of the disease and the etiology, but nowhere in that document did it say, ''Oh, by the way, if you have a death or if you have a hospitalization, code it to this.''

I think the proper place for establishing a code for SARS is at the international level. I am looking for those groups at various levels to give us advice or give us a code. I do not care what code it is, as long as we have a process to document it and push it forward. I think the results from the MRG should end up in Dick Thompson's media updates that go weekly around the world from the WHO.

C. ROONEY: Yes. I think you put it very well and made very clear the urgency of deciding on a code. You need to be counting these cases now, not trying to find how many there were in six months' time, so we need a rapid process.

L.A. JOHANSSON: When we discussed SARS in the MRG last week, we tried to find out which U codes countries had already used for some purpose or another. The first free one we found was U–04.9, so what we tried to do is to send a message to another forum, the Update Reference Committee (URC), their discussion forum, and say, ''This is what we found, could it be possible to do, and will this meet with any difficulties in any other countries?'' I do not think that we should wait for the WHO to send us a code. When HIV appeared, I think it took WHO 2 or 3 years to distribute a code, and by then every country had already found some other code.

C. ROONEY: I agree. This is one that we actually need to do rapidly. We have the structures. We should be able to do it. One of the problems is that I think people became a bit confused about which end of the U codes they were supposed to use and not supposed to use. We thought in the MRG that we could claim U–04, but then it appears that actually in some countries that may have already been used. Does anybody know within your own country, or in others, of U codes having been allocated already? It is not all the countries, but we know that the United States used the U–00 to U–03 for the terrorism codes without international consensus.

D. GLENN: We meant to use the right series, but we wrongly picked the beginning instead of the end.

C. ROONEY: Anyway, we need to make sure that that process gets finished. I agree that it should then be up on the SARS Web site at WHO with links from everybody who is trying to keep these things up to date.

Using intervals

C. ROONEY: Now, how should we be using durations or intervals of disease? Are they helpful in trying to select underlying causes and trying to decide whether things are in a correct causal sequence or not? Some coding advice, please.

D. GLENN: ACME has a real serious problem with that. We used to reject all the records where the duration specified that it was out of sequence, and with ICD–9 built in, an intentional reject. But we still have

problems with it. We can stop the sequence, but then we have problems when we apply the modification table. So I am not totally satisfied that we are doing that right at all.

L.A. JOHANSSON: I would say that interval information is absolutely helpful. We try very hard in Sweden to get the durations, both in Part I and in Part II. It is when we get to ACME and try to implement this into the system that we sometimes encounter a problem. But certainly it helps very much to see how long a person has had a disease, whether you would consider it serious or not. I could see perhaps a further development of automated software taking those durations more into account.

C. ROONEY: Our experience is that we get the durations on about 30 percent of deaths, and we get quite a number of difficulties. You have what looks like a perfectly acceptable, sensible sequence, but for some reason they said that the thing on Line ''a'' they had for 10 years and the thing below it for 5 years. Otherwise, it would be fine. You do not know whether they mean that was when it was officially diagnosed or when the disease process started. So we actually do not find that the intervals are very useful. But again, I think it may be fashions of certification.

Using outside information

C. ROONEY: How should we use information from sources outside the death certificate to code cause of death? We had some talk about this previously, in fact, about using police reports and transport department reports and all sorts of other things. So you have a death certificate, but you have stapled to it a police report of an accident or an incident or something. Should you use it or not?

R. BECKER: Well, let me just start with this. I think that legal statistics are for lawyers. We are discussing medical, statistical, and epidemiological analysis and data. In my opinion, we should use additional sources of information, in addition to the death certificate. I think it is valid information when you can trust in it. How to define it is another discussion. For example, for external causes, in many countries, very often if you do not use other information, you will never have the external underlying cause. Also, it is linked with the previous discussion about confidentiality. Sometimes for some diseases, you have records in the program, the control program for those diseases, for example, for AIDS. So why can it not be valid to take information from that program? It should be organized by type of sources, how, when and if I can get additional information. In my opinion, any valid information should be used to improve the quality.

H. ROSENBERG: I would say I partially agree. The reason I say that with some hesitation is this. Part of our challenge is to have internationally comparable mortality statistics. Thus, to the extent possible, we should be doing things in the same way because if we do not, then we know that our data are not going to be comparable. On the other hand, I recognize from working in the Caribbean area that external-cause information is often not available at all, and so you have to go to police records to get information, for example, about violent deaths. I think what we are doing as a general operating principle is to think in terms of comparability of data. I was very impressed when Eric Jougla presented the charts, the maps of European death rates by cause of death because immediately you can begin raising questions about the epidemiology of the diseases and the factors associated with differentials in suicide rates and whatnot. I think that the predominant principle needs to be maintaining comparability, and, secondarily, we have to deal with the countries that have incomplete data and need to draw on additional information. Otherwise we are always going to have that tradeoff.

In point of fact, we accept the problem of the lack of perfection in our data when we apply the coding rules because these rules do not always come up with the right answer. However, if we apply them consistently, we know at least that we can compare the data between countries, and we know the coding will be the same.

R. CASEY: Harry [Rosenberg], it is well and good to say we should be thinking about international comparability, but if a country has access to information that other countries do not have, which enables them to get a higher quality data, then they should be taking advantage of that.

In Australia, we have ready access to all coroners' information, which I know they do not have in other countries. We have access to all police records where it is input into an autopsy or a coroner's report; we also have access to a number of our cancer registrars. Therefore, it would be stupid for me not to use that information just to maintain international comparability.

C. ROONEY: I think it also works a little bit at the other end of the spectrum, where you are in a country in which the death certificate may only have ruptured liver on it, but the police report tells you that this was a pedestrian that was hit by a bus. If you do not have it on the medical certificate, it is not comparable to a country where there is a section that gives a description of how the accident occurred, or how the injury was sustained.

So, I think, to be honest, it is very difficult to get comparable data on death from external causes. I think one of the reasons for that is because the data comes from different sources in different countries. Different people are allowed to certify the deaths, different types of investigation have to be done or do not have to be done. They can be certified without any cause, or they cannot. I think it is a bit too purist to say that if it is not on the death certificate it will not be comparable. It is not going to be comparable anyway, but you can try to get the same sort of information from whatever sources are available to you. This is a personal opinion.

R. BECKER: We are sharing what we already discussed several times, but what is the solution? Are we assuring comparability, not recommending different sources but the death certificate? I do not think so. So what is the solution? What can we recommend?

C. ROONEY: Keep trying to improve it all, and more research needed. You always have to conclude more research is needed so you can apply for more funding. It is the only valid scientific conclusion.

Selecting Main Injury

C. ROONEY: How many people work in countries where they used to do a main injury in ICD–9 or before they automated coding? Hands up. Canada, U.K., Scotland, Germany, and Australia, so there are a reasonable number of countries that used to do it.

It has been a recommendation since ICD–6, so it always surprises me that not very many countries do it. Lars [Age Johansson], who is on WHO and ICD, tells me that it is because WHO does not ask for the data tabulated by main injury, so people do not feel a great incentive to do it. Our health planners find it very useful. They want to know how many people die of skull fractures, as well as how many people die due to road traffic accidents. One is for prevention and the other is for planning health care, trauma centers, that sort of thing.
ICD–9 had a very simple ''precedence'' list. In ICD–10 it says follow the rules, but the rules are relatively difficult to apply, quite often, in injury deaths. Again, there is some work being done on this by the MRG and somebody in Injury ICE.

L.A. JOHANSSON: The problem, if you follow the current instructions in Volume 2, is that you will in most cases come up with a completely useless code for the main injury, namely, ''Other and unspecified multiple injuries.'' So what we are trying is to devise some kind of mechanism by which you could select the most important injury. You would, in principle, apply the selection rules, and there is no sequence for which you have some kind of priority list.

C. ROONEY: I think the MRG will try to clarify the instructions of when you can apply sequence and when you cannot. Whether we can sometimes get round this nuisance of ending up with ''other unspecified multiple injuries'' by applying a rule like specificity, do not choose an unspecified description for the disease or condition if you have a more specific one for the same.

But then the ICE on Injury is another international collaborative effort, and I am amazed that I am the only person in both ICE groups who is in this room at the moment. They are getting data from several countries and have a meeting in Paris next week to set this up. We shall try and work out a precedence list that would work in ICD–10.

So if the other solutions that the MRG can provide in terms of using the rules still do not provide you with the best main injury, not underlying cause, we would develop a precedence list that would enable you to select something that was useful for tabulation. The final question about that was, ''If we can do that, can they program it?'' I think the answer was that you can program anything as long as it is clear.

D. GLENN: We have said since 1968, we have had all the injuries, so would you tell me how you want the most important one picked? No problem, we will give it to you.

C. ROONEY: Fabulous. That is a promise.

Special Presentation: Developing an Automated Mortality Coding System in Denmark

Morten Hjulsager, Division of Vital Statistics, National Board of Health, Denmark

The background for my presentation is two things. First of all (1), I would like to share some information about a project that is currently being undertaken in Denmark. Secondly (2), the Danish Register for Causes of Death hopes to receive your expert advice and opinion on this project.

The Danish Register contains and is built upon a death certificate of two pages. The first page contains the civil information such as personal security number, name, and address. The second page contains the medical information, namely, causes of death and results of examinations. Up until now, the coding has been on a manual basis, and since 1995 we have used the ICD–10.

The Register is used rather extensively, both in the public authorities and in the research area. At the moment, we have started to carry out a project that has two major components, the first (1) being an electronic reporting system; we want to collect the death certificates in an electronic manner, compared to now where we have paper certificates being filled out and sent to the National Board of Health. The second major component (2) is to introduce automated coding.

The purpose is to ensure data quality and consistency, both for Danish purposes and, of course, for international statistics. We want to speed up the process of updating the Register. At the moment, the last year it was published was 1999. We hope to have 2000 finished at the end of this summer. Our aim is to have a maximum lag of 12 months between the year of the statistics and the time when the results can be published.

One of the major challenges in this project is that we would change the current situation regarding coding cause of death from being a centralized task to being carried out at the local level by the health personnel, physicians. We will try to institute full electronic reporting, so that it will not be possible to report using paper versions, either for Page One or Page Two of the death certificate. We would base this on the Internet and, particularly, we will use the Microsoft.net standardized technology.

We will develop an application that the doctors can access via the Internet, and where they can report and send the death certificate to the National Board of Health. This is a difficult task because there are a lot of logistics to where the certificate moves around in the Danish system. A lot of different authorities have to be taken into account here, but we believe it is possible. The principle would be that compared to the current situation where we receive a free text on the death certificate, we shall ask for ICD–10 codes directly and will therefore receive them from the physicians when they fill out death certificates. We would also like to introduce ACME. However, there will be in this process no need for text regulation, so the digital part in the Danish system will not take place. This means that we would like to integrate the ACME physicians' statements directly into our cause-of-death system. The targets are 100 percent electronic reporting, and that all natural death codes can be coded automatically by ACME.

As I mentioned, some of the core elements can be done rather quickly: Internet-based electronic reporting system. It should be, of course, easy to understand and easy to use, and we will try to make use of all the available new IT possibilities; PDAs could be one. Decentralized coding by health personnel will require training, but we also believe that it could give us a reduction in the burden on respondents.

We have at this moment quite a heavy task in communicating with the physicians on what they actually need with the free text that they put in the death certificates; this would give them an opportunity to be precise. We also believe that it is the physicians who know exactly what has happened to the patients, so they, at least in principle, should have the detailed information about the history of the patient and, therefore, should be able to give this information quite precisely.

We based this on a tradition that can be tracked back to the 1970s when the Danish National Patient Register was started. For some decades, doctors in the hospital sector have coded to the National Patient Register, so this is not a new exercise for them. Case-mix systems (DRG's) have been intensively introduced in Denmark over the last 5 years, and therefore there is quite a lot of focus on coding.

We believe that dissemination of data is one of the cornerstones in making this turn around as we want to; we want to give at the local level a possibility for use of these data in their activities such as health planning, health promotion and health prevention, and health quality assessment.

In our current situation, we have death certificates on paper sent to the National Board of Health, where they are coded manually and put into the Register. In the proposed system, we will receive the certificates from the hospitals in the primary care sector through an Internet-based reporting system. These reports will then enter into our back-end system that is placed in the National Board of Health. They will go through ACME. A part of the certificates will then enter directly into the Register and another part would have to be handled on a manual basis.

Another way of giving you this picture is that we have a reporting client that makes use of the Internet. We have ACME as the automated coding system, and we then have also some manual coding. So we estimate the relation to be 90 percent versus 10 percent.

Thank you.

Feedback

D. GLENN: NCHS, particularly at Research Triangle Park, are delighted that you have chosen ACME as an international system. But please understand that the system requires a specific set of multiple-cause codes. The coding instructions are tremendously hard to apply. If you do not put the right codes in, you will not get the right underlying cause.

We have some codes that we call ''created codes.'' They are not in the ICD; they are done simply to make ACME run. If you look at that and you say, ''I am not going to use them,'' you are going to get the wrong answer. So please be sure you understand the multiple-cause coding rules before you take that system and think you can put any codes through it and get the right answer. It really concerns me.

M. HJULSAGER: Well, of course, that is clearly an important concern to take into account, but in the system we think there will not be really any changes in the data flow compared to the one we have today, except that we will do the collection of the certificates electronically, and we will ask for codes instead of text. Then, of course, we have to implement ACME into the Danish cause-of-death register.

H. ROSENBERG: There are a lot of things that worry me about the model. There are some things that are very desirable about the concept, but the devil is in the details, and there are some very problematic things in the details. Conceptually, what you are losing that you now have—if I understand you correctly—is the potential of using the free text at the national level as a research tool. If you are only getting ICD codes, you would be losing an enormous amount of detail that is already available in the free text format.

The other thing is that you have the physician or a medical assistant doing the coding. The mortality medical coding requires a high level of specialized expertise, as Donna [Glenn] said. It requires enormous experience unless you move to another level of automation, which is what we call MICAR and SuperMICAR, where, in fact, you can translate natural language into intermediate codes and finally into ICD codes.

I would worry a lot if you are losing the free text capabilities at the national level as a research resource because it is invaluable for research. The idea of having the data entered at the source is something that is immensely attractive because you can do querying, editing, and tutoring at the source level. While that is desirable, the other things are quite worrisome. I am in full agreement with Donna [Glenn] that the system you are proposing is problematic.

L. CHRISTENSEN: I am Lila Christensen from Denmark. I understand your concern. However, there will still be room for free text; it just will not be coded. Instead, it will be used for the coders in very difficult situations for the 10 percent that will require manual coding. We are saving all the images of what they have brought in, so we will always be able to retrieve it.

L.A. JOHANSSON: In Finland, there is some kind of mixed system, in which they get both the full free text and a code assigned by the doctor. Then the codes are checked at Statistics Finland, and I understand that they have to change about 20 percent of the codes, because they are not correct. Then of course, if you were to apply ACME, you would have to take all those modification rules into account. So I think that you would need to code more than those 10 percent. Sometimes you have to make changes to the codes, depending on other information on the death certificate, surgery, accidents and whatever. I agree with Harry [Rosenberg] that you should absolutely include the free texts, but you need somebody who is specifically trained in ACME coding to check the codes before you enter them into ACME.

M. HJULSAGER: I think I should specify one thing. The physicians will not do coding of causes of death. The physician will give us in codes the same information they already do concerning diseases, and in the future, the free text in the certificate will be put in ICD–10 codes. So they will not be coding in respect to causes of death; rather, they will be delivering us the information in codes instead of in text.

C. ROONEY: I think there may be a bit of discussion at cross purposes. I think the thing is that the codes that you have to put in for the free text as input to ACME bear a completely different set of rules than the codes you would put in for the same piece of free text as the main diagnosis in a medical record. You have to be trained to code in a different way from the way that they are coding now. So for the same term, depending on whether they put it on a death certificate with other terms or as a diagnosis in the medical record, they will have to apply different codes. Otherwise you cannot put it into ACME.

M. HJULSAGER: So if I understand you correctly, there has to be a transformation of the medical codes before they can be entered into ACME.

C. ROONEY: Yes.

M. HJULSAGER: This, of course, should not take place at the medical level, if you understand what I mean.

C. ROONEY: No.

M. HJULSAGER: But in the central system.

C. ROONEY: But you cannot convert the code. You need all of the text that is on the death certificate to derive the correct multiple-cause codes for each entity on the certificate. You must start from the whole certificate and all of the text, and the positions on the certificate of each piece of text to get the right multiple-cause codes.

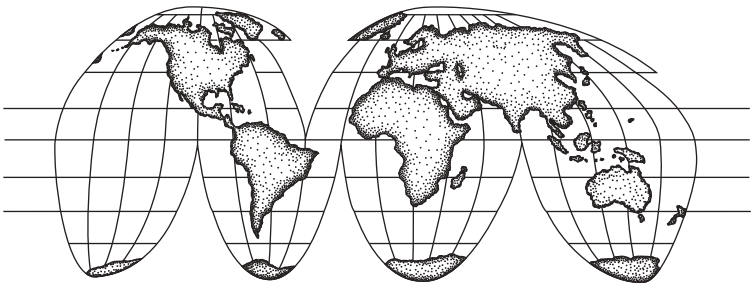
S. NOTZON: I have a couple of comments. One of them (1) is that I agree with a lot of the suggestions, warnings, or concerns. Multiple-cause coding requires a lot of training. You would not want to try to train your physicians to do it. That would not work, and it would be quite expensive.

Number two (2), for countries that are in the process of moving to the use of ACME, those that have tested the quality of their manual multiple-cause coding on an experimental basis have often found big surprises. In other words, let us say that they take a sample of death certificates, code them manually, manually select the underlying cause, and then use those multiple-cause codes to select the underlying cause via ACME. When they compare the two, they often find quite large differences. That is because multiple-cause coding is a very complex activity. So I think you need to take that into account.

C. ROONEY: It is a very interesting idea, but I think it is something you would really have to pilot and then redevelop and then test it again. I think it is such a huge change, that you are going to have to test whether it works in a sample first.

SESSION 10

Knowledge and Data Dissemination



Session 10: Knowledge and Data Dissemination

Graham Jackson (moderator), General Register Office for Scotland

Editor's note: Most presentations in this session included demonstrations of various software programs.

Under the knowledge theme, Ron Casey from the Australian Bureau of Statistics will be describing the bulletin board that has been set up by his department to cover our interests in automatic coding and coding systems and to provide a forum for sharing our experiences in using such systems. The establishment of the bulletin board was a direct outcome of the second ICE conference here in Washington, DC, 3 and a half years ago. As Ron will tell you, to date it has been underutilized, but I am sure that he can show us what we are missing so that we will all go away from this conference fired with enthusiasm for this product. As Ron is keen to discuss increases in usage and to seek comments from everyone about how they think it might be used in the future, we are to have some discussion on the bulletin board immediately after Ron's presentation before we move on to the second theme of this morning's session, data dissemination.

As a previous boss once said to me, ''Graham, you must move from process to substance.'' We all, no doubt, find the coding software process interesting and indeed challenging. As, I think, Sam Notzon said to us earlier in the week, most of us really want to analyze the data as well and also to assist others to analyze the data, but we all know that the large data sets that we are now collecting seem to get ever larger year by year. This is not just in terms of the accumulation of data but also in the addition of more variables every time they set up a new system. We do need to have appropriate software tools to help us do this analysis easily and in a straightforward way. In this session, we shall see four different products that are used in four different countries, which befits this international conference in three different continents: four different approaches to using software to assist with data dissemination.

We have four speakers. First, Ron Casey will be doing a second presentation; he will move on to give us a brief demonstration of the product that is used in Australia in a ''Supercube,'' the model of storing data, and how this is used for producing out put. Then Gerard Pavillon from France will give us a demonstration of a SAS-based system that is in use in his department. Third, Yelena Gorina from NCHS in the U.S. will be showing us some data analysis covering quite a wide range of topics, including mortality statistics and related health statistics, using a product called ''Beyond 20/20.'' Finally, from Statistics Canada, we have John Menic who will be showing a system called ''IRMA,'' which is essentially an in-house product that may well be interesting to other people because, I think, very often you do find that the commercial products that are available satisfy some of the things you want but not necessarily everything you want. That is why, of course, some countries decide to try and write additional bits of software. John will show us how they developed this in Canada.

Automating Mortality Statistics Bulletin Board

Dr. Ron Casey, Australian Bureau of Statistics (ABS)

What I want to do today is briefly introduce the bulletin board, give a very quick demonstration, and then facilitate a discussion as to how we could be better utilizing the bulletin board.

The concept of having a bulletin board was raised at the 1999 ICE plenary meeting, and again at the ICE Planning Committee meeting in September 2000. At the 2000 meeting, the Australian Bureau of Statistics (ABS) undertook to host the bulletin board on the ABS Web site. I might stress now, and I shall probably stress it again about six other times during this ten-minute talk, that it is not the ABS's bulletin board. It is our collective bulletin board that the ABS has undertaken to host on its Web site. It was not a smooth transition to create it, but we managed to launch the bulletin board in November 2001. As of today, we have 90 registered users in 26 different countries.

The bulletin board can be used to share information through announcements, but its most powerful use is the ability it gives people to initiate and undertake discussions. I am sure there are a number of topics that could be appropriately discussed on the bulletin board. A number have already been identified here this week that we could be discussing on the bulletin board, rather than by people sending e-mails to each other or communicating by teleconference. The bulletin board is always there, and anyone can use it at any time. There are no constraints about different time zones, and any discussion can remain as a permanent record, for existing and new users to read at any time in the future.

For those of you who do not know how to access the bulletin board, there is one Web address where you register, and then once you have registered, you go to another address to log on to the bulletin board.

The bulletin board is in two sections: (1) one that is an information-only section; everyone has only ''read access'' to that, except the database managers. This section is used for things like announcements of new software versions. (2) You will find that the area that you will use the most is the message board. All registered users have ''author access'' to the message board and that is where you can start and participate in discussions, question and answer forums, etc.

At the moment, I feel that the bulletin board is quite underutilized. Talking to a few people this week, I have gathered that a number of people are reading messages, but the messages, to date, have largely been posted by the database administrators. What we need are more discussions put up on the bulletin board, and more people writing comments and participating.

At the end of the day, it was actually identified as a need at the last ICE plenary meeting, and I suppose that might be a point to consider when we have the discussion. Is there still a need for the bulletin board, or is it just that people are finding difficulty in identifying what sort of issues they could use it for?

I might just add that the ABS has a number of these bulletin boards. We call them discussion Web sites, and they cover a number of different subjects. For any enhancement that we would like to make to the bulletin board, there is a need to maintain ABS consistency. What that means is I cannot ask for an enhancement just for our discussion Web site. It really has to be an identified need for everyone's discussion Web site.

Having said that, there are a few enhancements that we have been making recently. We just installed an e-mail notification system, which means that you can nominate particular discussion categories, and you will receive an e-mail when there is an update to any document in that category. We are looking at other enhancements as well. One possibility is to limit the number of users for a particular category, which means that two or three people could have a confidential discussion in a particular category if they wished to. There are a number of proprietary software packages that, apparently, have a lot of enhancements for these sorts of databases, and the ABS is currently evaluating a number of these.

Discussion

G. JACKSON: The first and most important question that Ron [Casey] posed was, ''Is there still a need for this bulletin board?'' My feeling is, ''Yes, there is,'' but I would be keen to hear any views from the floor on this matter.

C ROONEY: I am Cleo Rooney from England and Wales. I think there is very definitely a need, but I think people need to know to whom it is open. Can anybody join, or do you have to be a member of some particular kind of organization or be using particular software?

R. CASEY: Well, basically we are trying to restrict it, that is, we do not want to have open users. At the end of the day, the Bureau of Statistics is concerned that someone could actually come in and by some means hack into the ABS Web site.

With due reason, we have the most secure Web site in Australia. The Australia Department of Defense has come to look at our firewall. People know about this, so we get 80 serious attempts at hacking into our Web site every week. It is a major concern.

When people register, they are asked for certain information, not only their name, but for whom they work. Ann Wellington and I, as the managers, make the decision as to whom we are going to let in. We shall let in everybody in this room. There is no problem about that, but occasionally we get someone who is just sort of surfing around the Web; they come along, and we get so-and-so and such-and-such. They do not want to give us any information about themselves. Even then, we might just dismiss them out of hand. We will actually ask them whom they work for; that usually shuts them up. Basically we shall not allow anyone without a legitimate need to register.

L. GERAN: I am Leslie Geran from Canada. Can you do links to other sites? I am interested in being able to have discussions and references to comparability studies. There are all these studies all over the world, and I want to use the bulletin board as kind of a bibliography or archive for them, not only as a site for discussion but also as a place for people to do research. How would I do that or could I do that?

R. CASEY: Well, just open a document where we have a link to the U.S. National Vital Statistics System.

L. GERAN: So everyone with a comparability study should just send you an e-mail or send the bulletin board an e-mail with a link site?

R. CASEY: Yes, and I will just post it on the bulletin board. Do not send me an e-mail; that is the problem. If you actually look in the bulletin board, there are a number of things there where we might actually say, ''Here's a response to a mortality forum from Estonia posted by Ann Wellington.'' Ann put it up on behalf of someone else. Whenever someone puts something up, his/her name will appear after the document because we really want people to be posting directly to the bulletin board rather than sending us an e-mail. So to answer your question, yes, all you really need to do is just post it on to the bulletin board with a URL link, an Internet link to wherever you have stored your comparability study.

L. GERAN: All right, so anybody in the room, please, if you have a comparability study, put it on the bulletin board.

G. JACKSON: Ron, would it be better, in these circumstances, if people were at least able to submit a short abstract along with the link instead of just putting up a bare link?

R. CASEY: Yes, I mean, you can do anything you want. I just picked that as an example. There is a little bit of a text there but you can put in anything you like. I was just answering Leslie's question, but yes, you can embed links and documents, if you want to.

G. JACKSON: I certainly think the comparability studies are a very good example of how we can share information. As Leslie has suggested, make sure to place links there that will take users to more detailed Web sites. I know that the Office for National Statistics (ONS) in London has a good Web site, with a section about ICD–10 comparability studies. That is something that is certainly worth looking at. I know it can be found if you look at the ONS Web site, but it would be good to have the link on here as well.

R. CASEY: I will create a category on the bulletin board for comparability studies.

G. PAVILLON: In addition to comparability studies, I think that there should be a call for documents on certification training. The item already exists on the Australian bulletin board, but we will send you documents on certification training. It will be good to centralize at this site the different productions of different countries.

G. JACKSON: Let us also post copies, if possible, of death certificates in Adobe format, or would PDF documents be better?

R. CASEY: A link to a home Web site with that information would be better.

PARTICIPANT: I think there has not been too much work in the area of multiple-cause-of-death analysis, so maybe you could also have a section on that.

MR. CASEY: Yes.

S. NOTZON: I am Sam Notzon from the United States. Ron, I know that you have covered the issue of security concerns with your Web site, but in discussing the use of the bulletin board with a lot of people, the recurring theme that I hear is that people forget their passwords, which tends to discourage them from going back. Is there a way that you can add a little check box that says, ''If you have forgotten your password, click here?''

PARTICIPANT: The password rules are very long.

R. CASEY: Yes, they are, and the reason is because of the concerns the IBS has of people hacking in. Unfortunately, it has to be that way. Even I cannot remember mine. We actually ask for a name; you have to have a first name, a middle initial, and a last name. Then your password has to be at least eight digits, and there has to be a mixture of alpha-numeric characters. Unfortunately, I cannot change that.

G. JACKSON: I think one clear conclusion is that we think there is still a need, and we have identified several new areas where we would encourage people to post items. So I think, Ron, you should go away from here with every hope that it will be used more. Let me encourage everyone to do this: work hard with your passwords. I read in an article in the in-flight magazine on the way here about the plethora of passwords being one of the curses of modern-day computing; indeed it is because we all have a range of passwords, and we probably all do much the same for different sites and then pin them up on notice boards or put them into drawers.

The Supercube Data Analysis Tool—Australian Experience

Dr. Ron Casey, Australian Bureau of Statistics (ABS)

What is a ‘‘datacube?’’ Basically, it is a tool for us to publish our data or disseminate our data. It is a multidimensional electronic data set, and that probably means as much to you as the term ‘‘datacube,’’ but hopefully, as I provide some more description, you will understand a bit more about it.

A datacube contains information that people can use to build their own tables. It is manipulated by a software package called Super TABLE©, which was developed by Space-Time Research. Space-Time Research is an Australian-based company, but it has considerable international operations, including contracts with people in the U.S., U.K., and New Zealand.

Super TABLE© is a very powerful user-friendly tabulation software. Any tables that you produce in Super TABLE© can be exported to any spreadsheet package. Of course, once the data is in a spreadsheet package, you can further manipulate it, including producing graphs. It allows users to undertake their own data manipulation, which is good because you can only reproduce a very small amount of your data in paper publications. In addition, when people have come to the ABS in the past for unpublished data, they have had to stipulate which variables they want in their table and in what order, for example X by Y by Z, before they submit their request. With a datacube, you are able to do this yourself and produce a table X by Y by Z; or Y by X by Z; or any combination you want.

The ABS has numbers of datacubes on many subjects, and these are all available from our Web site. A number of these datacubes have been produced for causes-of-death data. The first of these contained 1999 data and allowed tables to be produced using combinations of underlying cause of death, age, sex, and usual residence. We have subsequently produced similar datacubes for the years 2000 and 2001. Also, for 2001, we produced a historical datacube containing data on suicides for the five years 1997 to 2001, which covers the entire historical series of our ICD–10 data. We also produced another historical datacube for drug-induced deaths for the years 1997 to 2001.

It is possible to produce a datacube for multiple causes of death, and we have a prototype that we have been using internally within the ABS. However, there are no plans to publish a multiple-cause datacube at the moment. One concern is that we still do not have a user community that is sufficiently knowledgeable or comfortable with multiple-cause data, but the major reason is that we cannot cross-classify underlying cause with multiple causes because you would actually be cross-classifying something with itself.

All ABS datacubes are available from the ABS Web site. Anyone who purchases a datacube from the ABS automatically has access to the software for free due to the contract that we have with Space-Time Research. As soon as you download a datacube from the ABS, you are automatically linked to the Space-Time Research Web site where you can download the software for free.

Discussion

PARTICIPANT: Ron, you said that we can download SuperCube, but what are the characteristics of the import file? Will we receive guidance about how to construct the input file?

R. CASEY: I do not exactly know what you mean by an input file. Basically, when you get the super table, all the information is actually there within that table. It is quite a huge file, which is one reason why we have only put out one cause-of-death file per year for 1999, 2000, and 2001. If we did a historical series, this thing would be enormous.

C. ROONEY: I have two questions. The first one is this: you were saying you have to purchase these tables, but your actual published tables are downloadable free, are they not? The papers that you put out and other items are there on the Web site without people having to pay for them.

R. CASEY: There is a price; our publication would cost about 24 Australian dollars, and the cubes cost about 170. It might seem a lot, but comparing the number of cells you can actually put in a table with the number of cells you can put in a cube, with the cube you get far more information.

C. ROONEY: My second question is, did you have any problems with ensuring confidentiality of the data at that level of detail? Our office is very concerned about letting people construct tables from which they might be able to identify an individual in a county who had a rare disease or something.

R. CASEY: Well, no. The reason is that we made this decision some years ago to have special confidentiality rules for economic collections in a number of our household surveys. However, we decided that we would make special rules for cause of death mainly because if we confidentialize cells less than three, there would be a lot of information that people would never get. Consequently, we made this decision that we would go down to cells of one, but only if we are providing data at the State level, which means that we can provide data by underlying cause of death down to the three-digit or even four-digit level by sex and age, but not to a geographical level below State. Nor would we do that for, say, a subset of the population; we would not be giving out cells of one for, say, the indigenous population.

G. JACKSON: Thank you very much, Ron.

Using SAS to Analyze French Mortality Data—A Web Server-Based Approach

Gerard Pavillon, National Institute of Health and Medical Research (INSERM), France

I will make a short presentation on our new Web server using SAS software to analyze French mortality data.

SAS is a professional software that is frequently used in statistics, epidemiology, and other fields. SAS has a very large library of mathematical and statistical programs that are very well assessed. SAS also includes a very efficient programming language. In addition, SAS allows the user to produce maps, graphs and HTML pages.

This Web server has been developed for the French Centre of Epidemiology on Medical Causes of Death. Our main tasks are the production and dissemination of French mortality statistics. We have a very large database including mortality data since 1968, and we implemented the first Web server in 1997 because we had a lot of specific queries on these data.

This first server has been working since 1997, and it allows users to get numbers and rate of deaths by year of death, place of death for regions, départements, and large cities. These data are presented by age, gender, and causes of death according to a short list that we are using in France, but also according to ICD–9 at the four-digit level. For example, users can rapidly get information such as death by hypertensive diseases in 1999 for a region of France, say Provence Côte d'Azur, by age and sex. The overall mortality of France will appear in a second table. Users can also get the crude rates by sex and age.

For 6 years, many users have used this server. It was a specific development using C-language on a Macintosh. In 1997, which was a long time ago according to the computer scientists' standards, it was difficult to develop such a Web site based on a database. We have had about 20 queries a day from all over the world for six years without problems: no breakdowns and no viruses, thanks to the Macintosh. However, against the basic law of computer science, which says ''If it works, do not change anything,'' we decided to develop a new Web server.

The idea was to implement new indicators: standardized rates, geographical characteristics, avoidable mortality, sex ratio, etc. The complexity increased because we also wanted to present maps and graphs in addition to tables.

To present data, we needed to query the database, to compute the tables, then to derive graphs and maps. Finally, all this material had to be translated in HTML so that it could be presented in a current browser. SAS fulfils all these functions using only one software program.

Figure 1. Home Page of the Web Server

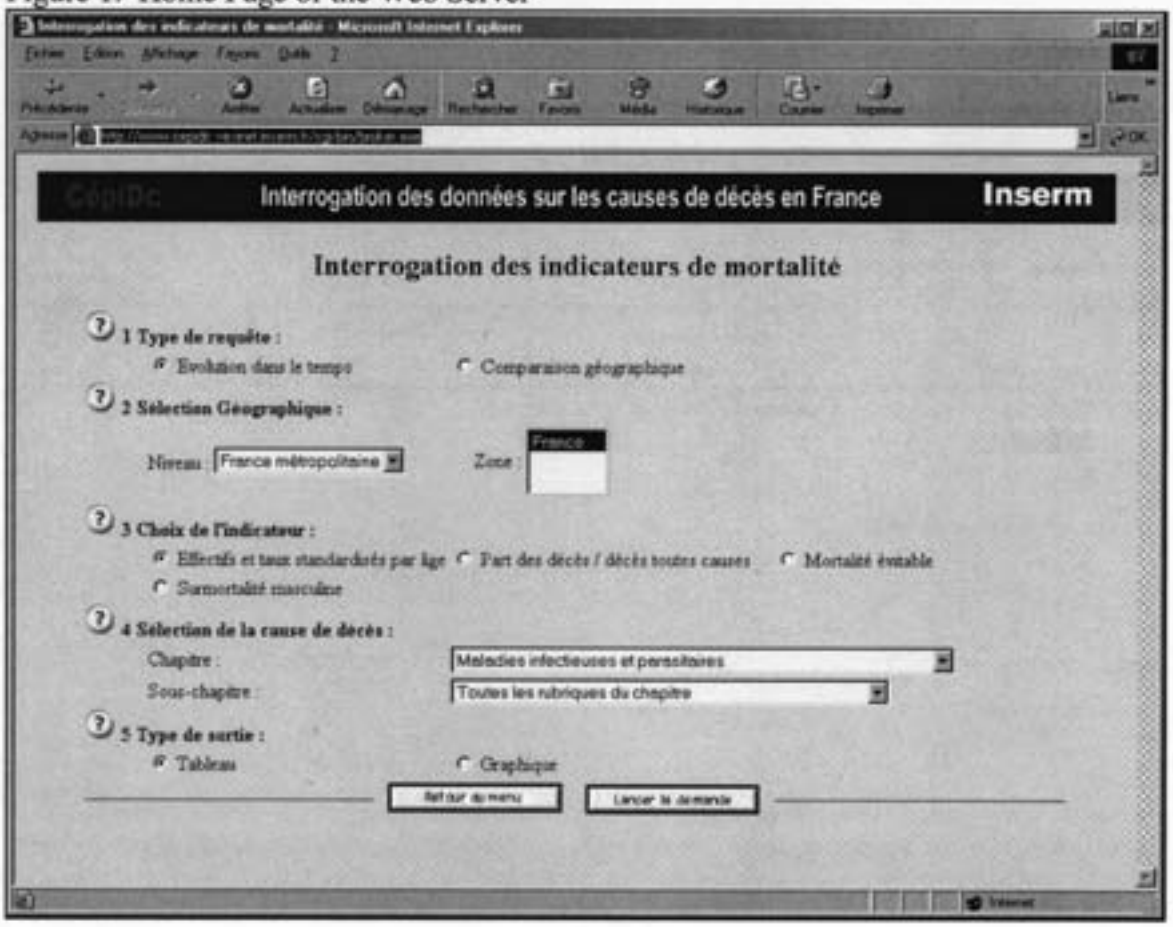


Figure 1 shows the home page of the server. A second page offers the choice between raw data or indicators. If you ask for indicators, the following interface proposes a choice between time evolutions and geographical comparisons. It is possible to select the type of indicator: standardized rate, avoidable mortality, sex ratio, etc. The cause of death can be selected according to the European short list.

You can obtain quite quickly this type of graph that shows the trends of AIDS between 1979 and 1999 by sex according to the standardized ratio (Figure 2). The map in Figure 3 shows the distribution of AIDS by sex according to the different French regions and you can see that Paris, the Southeast, and the Southwest of France are more affected that the rest of the country.

Figure 2. Standardized Death Rates for HIV Infection, 1979-1999

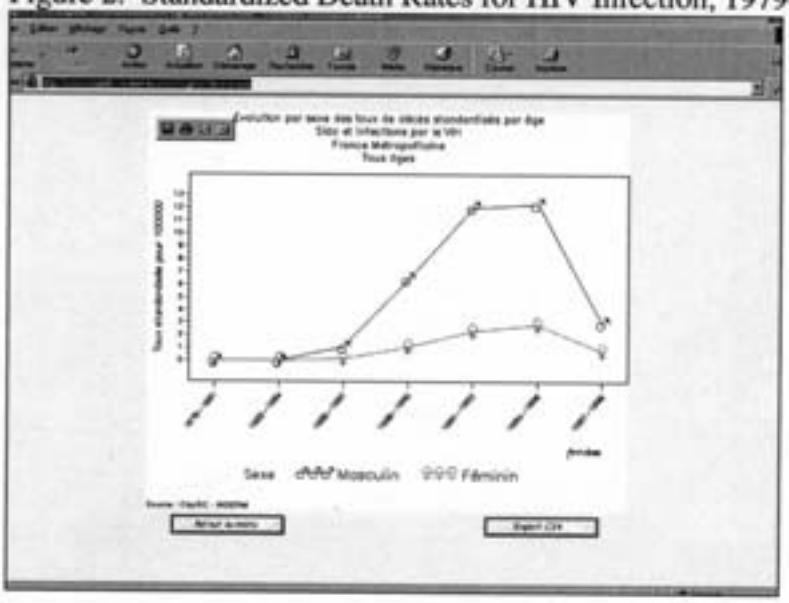
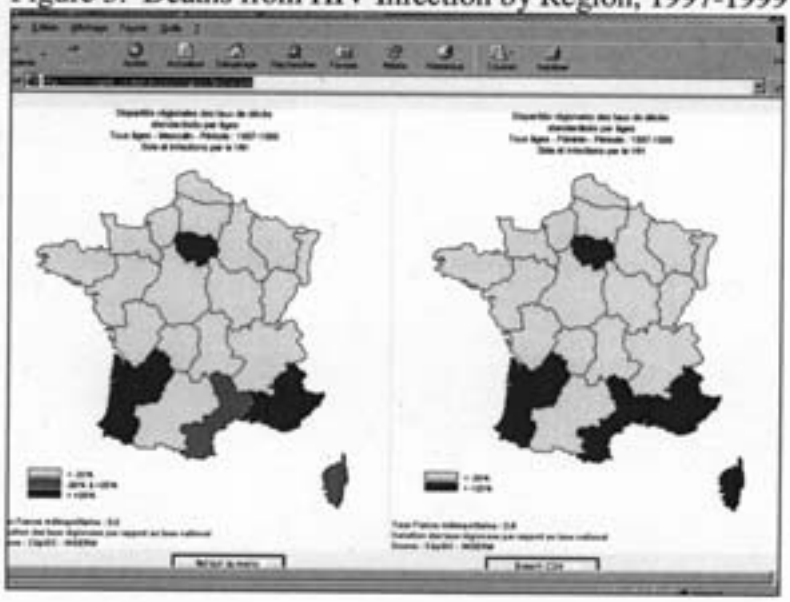


Figure 3. Deaths from HIV Infection by Region, 1997-1999



My conclusion is that SAS includes what is needed for this type of statistical data dissemination: data query, data processing, programming language, libraries, graphs, generation and HTML conversion, and it works. The main problem is that it is expensive. We are lucky because we are working in an academic context, so we have the 75-percent-lower price. However, you have to consider this is a huge library that covers a large range of functions, and it greatly facilitates the design of such a Web server.

Thank you.

Discussion

C. ROONEY: Do you have any links to your data dissemination on the bulletin board?

G. PAVILLON: Good idea.

S. NOTZON: I shall comment that the National Center for Health Statistics had some very specific reasons for starting this group, as for all of our ICE groups. One of those reasons was the fact that there are so many countries interested in developing automated systems. Since we could not possibly support all of them individually, we were interested in developing an international community of users who could, in turn, help others. Thus, we have these meetings to share information and to help to bring other countries into the fold, if you will.

One of the things that I have really been struck by over the course of the meeting is that there is a lot of sharing or trading of information, techniques, solutions, and approaches from one country to another. I think that is wonderful. I have spent almost my whole career in international activities; the idea of promoting international collaboration is very important to me, so I am really pleased to see it here.

Data Warehousing Using "Beyond 20/20"

Yelena Gorina, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

We have had a lot of queries and questions, and our agency was funded to create a data warehouse on trends in health and aging, which is a collection of aggregated data on aging from different sources in the United States.

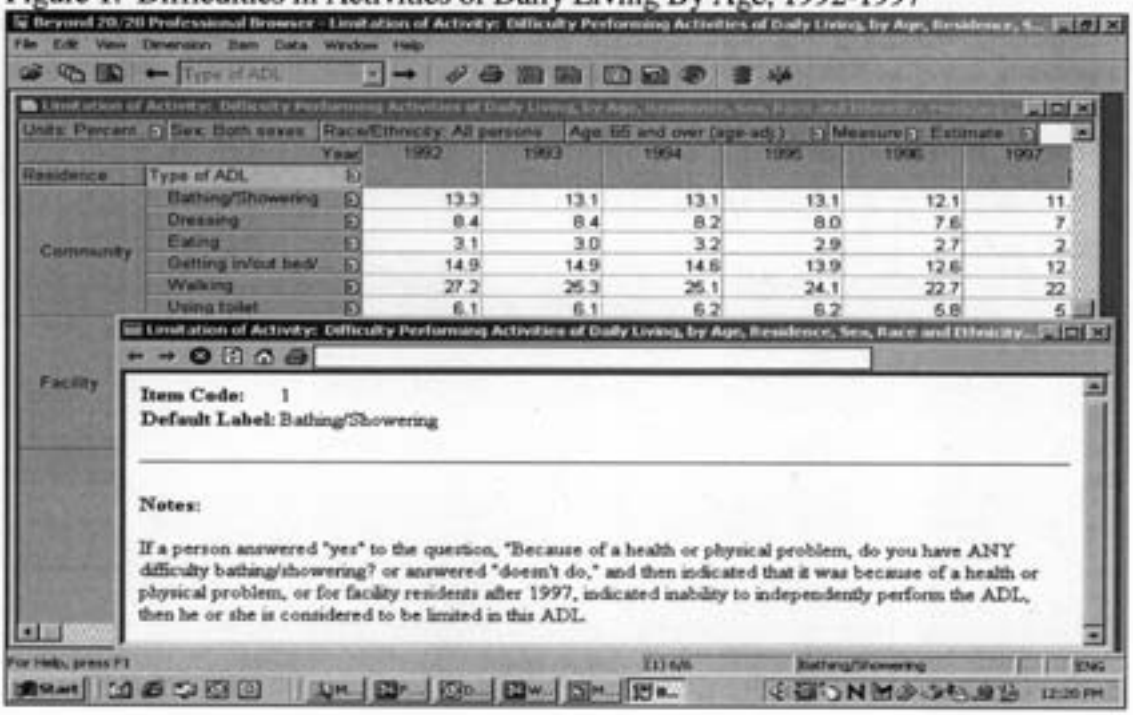
We worked hard to find the best software that would serve our purpose. Among the requirements were that it should be easy, user-friendly, easy to disseminate, utilize aggregated data, and allow us to put some common summary or explanatory messages to the users about our data. Such is ''Beyond 20/20,'' which is a Canadian-based firm that created this product. We purchased it from them. It is a bit like Adobe Acrobat, where you have a reader and a writer. We have a browser that we distribute freely, but we do have to purchase the software that we use to create our tables, the ''Beyond 20/20 Builder,'' which is reasonably priced. It includes a little tutorial on the Web, so if you open our Web page, there will be something to help the user.

The other features for which we chose ''Beyond 20/20'' is that it offers two ways to access the data. There is a way to download the browser and the table or just open the table and manipulate the data the way you want to. There is another way: if you do not have the option of downloading anything—for example, if you go to the library—you can use a query system that operates on the NCHS server, so you do not use your hard drive at all.

The other nice feature of ''Beyond 20/20'' is that you can use different types of missing data if data are not reliable, and you can see the results by age group, by sex, or by race. You can also build a map, with data for different years. You can save the data and do many things such as read the data into some other graphical map package or Excel.

We have to preprocess data: when we get the data, we analyze it and think about which measures are appropriate. We use SAS macros to create aggregated files that we store on the mainframe computer. At the same time, we make WordPerfect or Microsoft Word documents that include all the explanatory messages, and then ''Beyond 20/20 Builder'' puts it all together to get tables such as in Figure 1.

Figure 1. Difficulties in Activities of Daily Living By Age, 1992-1997



Our future plans include working on the teaching modules because we have so many topics now and so many tables. This is useful for students or professionals in the aging field. Another project is trying to translate our tables into Spanish. In ''Beyond 20/20,'' there is the option to use different languages.

Thank you.

Questions

S. NOTZON: Yelena, can you give us a little bit more information on the cost of ''Beyond 20/20?'' You said it is reasonable, but that may have a very different meaning for different people.

Y. GORINA: You pay for one license than can serve three administrative programs. On our Web site, we have another program on women's health by State, and the search program ASTMA is going to join us in using ''Beyond 20/20.'' The license costs us about $25,000 a year, so three programs can use it. We do not know exactly the number of our users, nor do we want to know because the cost of the license will go up if we have too many users.

Statistics Canada: Using IRMA to Access Canadian Health Statistics

John Menic, Health Statistics Division, Statistics Canada

I shall demonstrate a software program called IRMA, which was developed in-house at Statistics Canada to allow users to access our various databases. IRMA stands for Information Retriever and Metadata Administrator. It is actually more than one application. I will be showing you the information retriever aspect this morning, and I will just touch on the metadata administrator application.

IRMA is a reusable solution. It is used in several divisions within Statistics Canada. I first came across it a number of years ago where it was being used to access education data. We took the product and brought it into our Health Statistics Division, where we are using it now. It provides record-level access to various databases. This was important to us because we wanted to make a general tool for all our staff to be able to pick off any record and any value within any record that we have.

The Health Statistics Division collects and distributes not only mortality statistics but large administrative databases like morbidity. We have some sample survey databases like our Canadian Community Health Survey, and we needed a tool to be able to access all of them. We found that all these programs developed independently over the years, so they ended up being on different platforms and in different formats. When a new person came in, they would have to wind their way through a maze of data dictionaries, platforms, file types, and so on. IRMA gives them direct access to everything through one portal.

The initial function that we wanted to obtain from this product was a query function, but as it evolved over the years, there were three other functions that evolved along with the product. One (1) is a quality-assurance function. Typically, we get a new file from our Operations Division, and we load it up on a development database. We give data access to the project manager exclusively so that the manager can run a number of queries to test the data and make sure that nothing escaped the original edits in our Operations Division. 2) We also use it for data sharing. Basically, we share information with some divisions so that we no longer have to ask them to provide us with a file through which we can give them data access. Finally (3), it is being used for preliminary analysis, so analysts who are interested in a particular subject matter can go to various databases to see, at least in general terms, what is happening in their area of interest across databases.

Because it is record-level data, we are obviously very sensitive to exposing individual records. When you open up the product to get the splash screen that comes up, there is a note about data security. You will also see several categories of data on the top left window, beginning with vital statistics. When you click on one of those, such as vital statistics, it opens up and shows you the various databases that are available, such as birth, death, marriage, and divorce. When you click on one of the databases such as death, it shows you all the fields that are associated with that database that we have loaded.

There are individual fields, such as year of death. When you click on death year, you will see, on the right-hand side, the number of years that we have in the database. Now, you can go about choosing the years that you want to see or you can click the top button, which will give you all the available years in your query.

There are also grouped fields such as cause of death. If you click on that, you will see chapter, block, and three- and four-digit codes. If you click on the three-digit codes, again, you will get the list of all the potential values, in this case, three-digit codes; you can scroll up and down to find the one of interest to you.

I will run a couple of queries just to give you an example. I will search the database. If I am looking for acute myocardial infarction (AMI), it gives me a couple of potential values, such as AMI and another one. I shall double click on AMI; on the right-hand side, it has scrolled down to the appropriate value. If you are more comfortable with codes, I can the ICD–9 code 410 for AMI as the underlying cause.

Before I run this query, I want to show you a couple of other parts of the screen. About two-thirds of the way down is the query definition, which is a literal explanation of what I am doing. For death here, I have chosen ‘‘all.’’ For underlying cause of death I have chosen AMI, with total deaths as the default. Along the bottom of the screen, there is an opportunity to put all kinds of metadata into the database, and in this case, we have a description tab that lights up and provides a short description of what ‘‘underlying cause’’ means. You will also notice that there are other tabs along the bottom of the screen that are dimmed. This means that

they are available. If, for example, I clicked on ''vital statistics,'' you will see the warning lights and a note about birth and death geography, as well as a source note and a description note.

Now, if I want to run the query, I go up to the little lightning bolt icon at the top; I run it, and quick as lightning, I get 21 years of AMI data. Now, obviously, I want to drill a little bit deeper than that. While it is interesting to know how many AMI deaths occurred at the national level, I want to drill down so that I can edit that query definition. I can select additional fields from the left menu, for example, I can choose sex and 5-year age group.

In terms of what you can do with the output, we do not have any capabilities in terms of graphing or mapping because we decided to concentrate on the tool that gives us access to the data. We have invested a lot of money and time in products like ''Beyond 20/20'' and SAS. We have both of those products at Statistics Canada, and we invested a lot of time in training people to use them. Since they already knew how to use these products, why reinvent the wheel and give them something else to learn? Instead, we concentrated our efforts on getting the data out of the databases. Once you have the data you need, you can export them directly to something like Excel. There is a little box that opens up, and you can tell the software where you want to save it, including as an HTML file or as a comma-delimited text file.

Before you distribute something like this, of course, you may want to worry about small record counts. You will notice, for example, down at the bottom right, for males, where the age is unknown, and for females, 30 to 34 years old, there were only two deaths in this fictitious data. IRMA gives ultimate ability to set thresholds for suppression, and I think we have chosen three for this database. If I go to the option fields and click on self-suppression, you will notice those two values now have the word ''suppressed.'' On top of that, you can add random rounding as option, so I shall choose that, and now all the counts around it are zero to five. This is very useful if you have a large output data set and do not have to go line by line to check for the values; it will set everything for you.

Let me go back to the data and edit the query again. I am going to de-select some of the choices I made in terms of age and sex. Before I do that, let me go back to that 5-year age group. If I wanted, instead of aggregate counts, to look at the individual records, I would have the ability to do so. So for 5-year age groups, I shall select all the young people, and my definition of ''young'' is anybody less than 50. I shall run the overall query; you can see we have about 100 records or so. Instead of doing the ''lightning bolt'' query this time, I shall move over two icons to the ''view selected records'' icon. Now it gives me all 30 or 35 fields that are associated with those criteria that I selected, such as year of death, month, day, country of residence, and so. I shall scroll to the end where I have ''by the place'' and ''by date of'' information. I can drill right down to the individual record with this software.

I shall edit this again because you may not be interested in all 30, 40, or, in some cases, 1,000 fields associated with the database. You may be interested in certain fields for each record, for example, marital status and locality of death. There is a button that says ''view selected values.'' It is for those 107 records that met the criteria. Now I have those six or seven fields, locality of death, marital status, 5-year age group, etc. So it is a very powerful tool for getting right down to the individual-record level.

Now, let me de-select, as I was going to do in the first place, some of these things. This time, I am going to show you how we can define our custom groups, that is, make up our own groups. I will go to death month. So I ran this query. I have AMI deaths by month, but I was interested in seasonality, for example. I will edit this query. I will right-click on the code set and define my custom groups. A little box comes up, and now I have to do typing. I have given it a group name, ''Seasonal Ottawa,'' and I have to start defining the groups now. My winter is going to be from November through April this year, so I brought all those values over. I also defined spring, summer, which is June, July and August, and fall. I have created a new field: Seasonal Ottawa, with the groups of winter, spring, summer, and fall. This is a really useful feature if you are using large code sets and want to do nonstandard aggregation, such as by geographical codes. You can put 30 or 40 geographical codes into the groups of interest or even causes of death. If you want to find a disease, for example, you can pick and choose your ICD codes and put them into your own groupings. When I run this query, I will get AMI deaths by season, or at least by the seasons that I have defined.

Results are saved locally on the user's PC, so they can use those. The nice thing about this feature is that it is reusable between databases. For example, if I go up to the stillbirth data set and I click on month, I have those predefined values, namely, the individual months; there is a result by month, but it is carried over. The seasonal value I created for Ottawa—winter, spring, summer and fall—can be run for stillbirths as well. Again, if you are studying geography and you have nonstandard geography codes, it is useful. You can start looking at still-births, deaths, and births by those groups that you created.

While I am in the stillbirth file, I shall show you another feature at the bottom of the list of fields. We have something called ''rate,'' and I can do crude rates with the software. I have to define my underlying values, so I am going to get by 5-year age group and year. Also, you will notice at the top right that it says ''by population estimates, July first,'' which will be the denominator. If I run this query, it goes to the stillbirth table and pulls out the number of stillbirths by mother's 5-year age group. It goes to the demography or population table and uses that as the denominator, so it gets a crude stillbirth rate.

If I go back to the rate field, IRMA gives me the opportunity to use different denominators. People tell me that when studying stillbirths, it is often useful to divide by the number of births. Again, I will choose mother's age group and year, and then run the query. This time, it pulls the births by mother's five-year age group and uses them as the denominator to the stillbirths, so I have a new rate.

I mentioned that we use this software to share information among divisions, and it is fairly seamless to the end user. We have a reciprocal agreement with the Demography Division to share information, so our analysts can share the most recent data. They do not have to make a phone call and say, ''Ship me a file of your most recent demography data.'' It is already built in. Similarly, I said it was a reciprocal agreement. When the people in the Demography Division open up their version of IRMA, they see the vital statistics because they need birth and death information to do their intercensal estimates. There is a flag, so they do not see the rest of the databases that we have. They can query our data directly, and they have the most recent information available right away.

There is one more set of queries I want to run. I shall go back to death. If I were a researcher interested in asthma but had no idea what kind of frequencies were coming across the various databases, I could use this tool and search for asthma. It brings me down to ICD–9 code 493, and I would pick 2002 asthma. Obviously, the researcher would probably pick age, sex, and some kind of geography.

They can create another query and go to a sample survey that covers over 100,000 respondents. There are well over 1,500 possible questions, all grouped into these large categories. One of them is called ''chronic conditions,'' and one of the fields in chronic conditions is called ''asthma.'' Now, at the bottom of the screen, we have the question that was asked of the respondent, ''Do you have asthma?'' We have a little ''universe'' note there that all respondents were asked this question. So we shall select the people that said, ''Yes, I do have asthma,'' and run the query. What it gives us is both the sample count as well as the weighted estimate.

I shall run one more, hospital morbidity. I will go to the diagnosis codes; we have something called ''tabulating diagnosis,'' which is similar to ''main diagnosis.'' I will search for the term ''asthma'' again, double click, and I got the number of hospital discharges across all years. I will go back to ''year'' and choose the most recent year. Now I have 3,157 discharges for asthma in 2001 and 2002, that is, the people in the sample survey that said they had asthma, as well as the number of deaths.

The software is also multilingual or has multilingual capabilities. We have two official languages in Canada—English and French. An icon indicates where you can switch language. Everything on the screen gets translated automatically from one language to another, from the headers to the pull-down menus, and even the ICD codes.

The current health database contains about 43 million records and is growing. We have several thousand fields or variables available across these databases and six categories of the data, as you have seen. In summary, it is an easy-to-use tool; you could probably come up here now and start finding out how many deaths there were for any cause of interest by any geography or any of the other fields that we have.

One of my favorite queries was to find out how many people are discharged from hospital on Valentine's Day with a new heart. These things you would never find in prebuilt tables, obviously, so the training costs are very low. We typically get a new person up and running within a 5- or 10-minute tutorial, as I have just given

you, and they are productive immediately. This is an opportunity, a learning tool for them, too, because they can see exactly what kind of data holdings we have, and they have all the associated metadata with them.

IRMA is easy to maintain. There is an application for database administrators, which looks very similar to what you have seen except that s/he has the ability to edit some of the labels, add data sets and code sets, etc. very simply and easily. In fact, for this entire database that you have seen, the production database as well as the development database, we have one part-time employee working and maintaining all of it because it does not require any high-level programming language. It is a matter of updating various tables with flags and pointers and that sort of thing.

There is just one technical note. The statistical and metadata can be stored in any ODPC-compliant database, for example, MSSQL server, Oracle, or MS Access. We have used all three of these, but currently we are using Sequel Server for our statistical data; we hold it all together with an MS Access database for the metadata. We chose these because of cost and training, that is, we had a database administrator who was familiar with those products, so if the death data, for example, existed on a mainframe, we were able to have him move it down to a sequel database that was attached to the server, and then we were ready to go.

Thank you.

Discussion

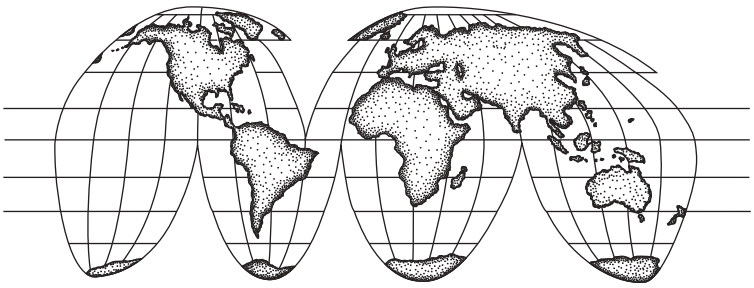
PARTICIPANT: I have a question about the free access of the data because there is a strong demand for data in this state. We are very frequently asked for data for Australia, Quebec, Canada, and so on. I think it will be a very good thing if access could be free. Data for a number of countries at the level of the European Union are not freely accessible.

My second observation is based on what I know exists in a number of Web sites. Could we imagine that the bulletin board could provide official links, labeled by country, that directly focused on the modality that is in each country? Thank you.

G. JACKSON: I think your comments suggest another item for Ron Casey's list. I should stress that it is for all of us to make the postings to the bulletin board. It is work for us all to do, to add to the bulletin board, but your idea is an excellent one. Thanks again to all the speakers.

SESSION 11

Panel Session - Prospects for the Future



Session 11: Panel Session - Prospects for the Future

Dr. Sam Notzon (Moderator), National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

I can say from my experience with four different ICE groups that if new ideas do not come along, they die very quickly. At some point, perhaps you want to declare success and move on. On the other hand, I think there are a number of other issues that this group should be addressing, so we are looking for help and advice and suggestions from you all.

We have four panelists today. Two panelists come from international organizations and have not been directly part of the ICE group, but they come from organizations that deal with mortality, ICD, and automation. We hope they can provide us with an outside perspective. We have two other panelists with an inside perspective, two members of the ICE planning group.

Ron Casey, Panelist

Australian Bureau of Statistics

Before I start talking about the accomplishments of the ICE, I would like to just give a special acknowledgment to the NCHS. Without NCHS, we would not have an ICE. I think it does not hurt to reflect on how generous they have been in sharing the MMDS software with the international community, how they provide support and training to people using the software, their production of regular software updates, and last but not least, the organization and hosting of meetings such as today. I think we should be thankful for NCHS for what they have done for us.

When Sam Notzon asked me if I would be on this panel discussion, he requested that I briefly go over the achievements and future directions of the ICE. I thought, at first, that this sounded fairly easy, so I readily accepted; however, when I actually sat down and thought about what I was going to talk about, I started to wonder, ''Just what is the ICE?''

Is the ICE a mutually supportive group working together to maximize the utility of the MMDS software and other automated systems, or is it a group aiming to improve the quality of international mortality statistics from a wider perspective? Without having to think too long about it, it became obvious to me that the answer is both, as reflected in the 1996 ICE plenary meeting recommendations.

I suppose one thing for the ICE to look at, and the question has already been asked in individual sessions here, is ''Are the 1996 ICE plenary meeting recommendations still relevant?'' Thus, I have a total of ten recommendations, as follows:

Recommendation (1) *is that an ICE stock-taking be undertaken to assess the success and current relevance of the 1996 goals, and to identify and agree upon future directions which the ICE might take.*

The ICE is a group not only looking at improving the MMDS and other automated systems, but also looking towards improving the quality of mortality statistics, in general. Therefore, for the purposes of this talk, I shall address these two aspects of the ICE separately.

First, looking at just the MMDS system, I feel that the ICE has developed the MMDS into a widely used international tool. It has provided international assistance and support in the use of the MMDS and other automated system software and effected much more consistent and comparable international mortality statistics.

Although we talk about the MMDS as an international resource, is there really a sense of international ownership? It was certainly an original aim of the ICE that the MMDS would have international ownership. I think we started off well. The task of building the decision-making rules for ACME was well shared amongst the international ICE members.

However, it seems to me that the ownership of the MMDS has fallen back on the shoulders of NCHS, and I wonder how and why that occurred? Maybe we all got too involved in the implementation of ICD–10; as this was such a major task and commitment of resources, it limited the time we could devote to enhancing the MMDS, and we let the ownership of the software fall back to the NCHS. As a consequence, some of us might complain sometimes that the software has become a bit of a black box. I get a new version each year, and we process our data each year with the new version, but do we really know the content of each new version? Do we know whether it has included all the Update Reference Committee's decisions? Is there sufficient testing of each version? These are the sort of questions I continually ask, and sometimes you only find out that there might be issues once you have actually started processing the data.

Of course, it is easy enough for us to complain that it is NCHS's fault when mistakes are found, and I admit I do that as well. However, I think if we are going to say that the MMDS is an internationally owned product, then all us here, as members of the international community, should be taking a greater role in ensuring that these words are put into practice.

Recommendation (2) *is that if there is agreement that there is still a commitment to international ownership of the MMDS, when new versions and updates are released, there should be a shared agreement of what the content is going to be, and a shared workload in undertaking the validation and testing before each release.*

Recommendation (3) *concerning the MMDS software is that full documentation of the differences between different versions of the MMDS software needs to be developed, as this is presently a vital information gap hindering the ability of users to fully understand our data.*

Another thing we say is that we have more consistent and comparable international data now that we are all using automated systems, and this greater consistency and comparability is certainly promoted as an incentive for new countries to adopt the MMDS and other automated systems. But do we really know that this is true? We have a gut feeling that tells us it must be the case. As we are now all using the same automated system or a similar system, surely our data must now be more internationally comparable, but do we really know?

Recommendation (4) *is that a study be undertaken to quantify the differences in international comparability between death data coded manually and by automated systems.*

In relation to possible future directions for the MMDS, it seems that despite the strengths of the MMDS, there is still reliance on significant clerical intervention and other front-end systems.

Recommendation (5) *is that ways of extending the degree of automation within the MMDS, particularly in relation to external deaths, need to be actively explored. Another possible enhancement to the MMDS would be the inclusion of non-English lexicons.*

Now, I would like to turn to the accomplishments of the ICE beyond the development of automated systems. As I mentioned earlier, we are a group of people who have come together for the particular purpose of undertaking international collaboration on automated coding systems. But having come together, what other things can we do, and what other avenues can we explore with the combined expertise and intelligence within this room?

Certainly, the ICE has initiated the establishment of a number of WHO Family of International Classification (FIC) Heads of Centers developments, in particular the Mortality Reference Group and the Training and Credentialing Subgroup, both of which met here last week, and reports of their progress have been presented at this meeting.

The ICE has also promoted quality improvements in other aspects of mortality coding and training, electronic registration, comparability studies, and all of these have been mentioned. In fact, we have had specific sessions on them at this meeting.

These have all been worthwhile initiatives, and I think the ICE should continue to undertake similar collaborative projects. This forms the basis of the following recommendations for future directions of the ICE. For brevity, I will group the recommendations under broad headings, without listing all the possible examples.

Recommendation (6): *I think the ICE should continue to work closely with the WHO FIC Heads of Centers, but in cooperation, not competition. Sometimes there can be the tendency for some overlap, and I think we need to really be making sure that what we do is undertaken cooperatively. The ICE also needs to maintain close collaboration with the Heads of Center subcommittees.*

Recommendation (7): *I think there can be more collaboration amongst members of the ICE beyond the common use of automated systems. Currently, we mutually discuss how we are processing data that we have already received, and I think there are certainly opportunities for the ICE as a group to be looking at other*

data quality issues, besides just how we are processing data through automated systems. That could cover data quality at the input stage, as well as at the output stage.

An example of a data quality issue at the input stage is the development of electronic registration forms. To date, we have tended to be a bit reactive to the development of electronic registration forms, especially to those registrars who wish to incorporate pick lists in their electronic registration forms. I think we should accept the fact that electronic registration forms have been introduced and will continue to be introduced. They are obviously going to be the way of future, and yes, we do not want people to use pick lists.

Recommendation (8): *Therefore, my next recommendation is that as a group, the ICE should be a bit more proactive in helping to develop electronic registration forms, while ensuring that they do not compromise the quality and integrity of the registered death data. There is also potential for greater collaboration after we have processed the data.*

Recommendation (9): *The ICE could develop an agreed format for multiple-causes-of-death data dissemination. That has been discussed already at this meeting, and I think having an agreed dissemination format would be a great help in enhancing the international compatibility of mortality statistics.*

I know from my experience talking to countries that want to adopt the MMDS system that some of them feel they just need to get a CD-ROM from the NCHS, plug it into their computers, and off they go. As we all know from experience, it is a lot more complex than that. For example, you need significant systems development, programming expertise, and resources behind you to effectively implement an automated system.

Recommendation (10): *Maybe there are more ways that the ICE community can help potential new users of automated coding systems, not only to understand how to use the MMDS software, but also to help them with the systems development they need to develop to support it.*

Thank you.

Grace Bediako, Panelist

Demographic Statistics Section, Statistics Division, United Nations

We are really pleased to be here to observe how the ICE group is progressing. This is the first time I have attended an ICE meeting, and we are particularly impressed by the mix of national statistics offices and experts from ministries of health, which is something we would like to see more of, especially in other countries and other regions.

From the previous presentation, there is a lot that has been accomplished already, but several questions come up, such as whether ICE can continue in the same form, whether there are other topics that they could consider, and what work is left for ICE to be doing.

Naturally, the United Nations Statistics Division sees the international collaborative efforts of this group, which have been an essential ingredient to the development of statistics both at the national level and international level. While international comparability does not drive national statistics development, there are elements of international comparability that do support efforts at the national level, for example, the development of standards and classifications, and, particularly, exchange of information and expertise amongst countries. These goals help to advance statistics at the national level, especially for countries that do not have the kinds of resources that would enable them to start off on their own.

I am sorry I missed the first day's meeting, so I do not know the extent of the automation that has gone on. However, I know that a lot of countries have done it, and there are many more countries that are interested in automation, such as countries in the developing regions of Africa, Asia, and Latin America. There is a lot that this group could contribute in terms of the development and spread of automation to other regions. Automation is particularly important, I think, because of the potential to cut down the time lag between the production of statistics and the dissemination of information.

I shall address the question of how the ICE could go forward from three perspectives. One (1) is from the original purposes established for ICE; the other (2) would be to sift out from the discussions messages that might lead us to identify some areas of work; and (3) then we also have our independent concerns or areas of consideration.

As I recall, the main areas covered in the purposes of the ICE establishment included information sharing. Clearly, that has happened, and a cut of information sharing for information sharing really can go indefinitely because development does not stop. I think the introduction or the further development of the bulletin board is a good input into this process.

Another area was to develop and improve existing systems. There are countries that are still interested in initiating work in this area or are already doing some work; both types would greatly benefit from the advice, input, and support that a group like this could give. So while a lot has been achieved on this purpose, there is still a great need in some countries, which stand to benefit more.

The transition to ICD–10 is another area, and here I am sure most countries have already moved to ICD–10. My question, and one we discuss in my office, is how will future revisions be realized? If the next involves a major shift, it means that this group would have to be resurrected, if it no longer exists, to try to bridge the gap. Or, do we need to find a way of revising these recommendations so that they are not dramatically different from what current systems are supporting? It should be a gradual process so that new classifications, new diseases, or new causes of death can be brought in as we go along. There could be a technical group that follows up on the changes that should take place.

The last area mentioned is technical support to promote the automatic system. An earlier presentation addressed this. We have made progress; the goal has been addressed. How much further could it go? That is a question that we could answer in our discussion.

An issue I gleaned from the meeting is lack of access to information. I recall that one presenter noted that if they had known of the ERN, they would have taken a different approach in the development of their language dictionary. Also, I think the presentation on the bulletin board highlighted the underutilization of the bulletin board. Perhaps this is an area that we can improve upon so that information is available. But how do potential countries access this information easily? That is something that could be addressed.

There is also the issue of comparability studies. There is a lot of interest in understanding the effects of the transition from one coding standard to another on how cause of death and other characteristics are coded. This is also one area that could be addressed further.

There is also the question of how medical and other records can be used to improve the quality of statistics. We are always striving to improve the quality of statistics, even as we generate and disseminate the statistics we have.

Another prominent issue discussed was training. There are a lot of training programs being developed, and there might be a need for supporting these training programs with exchange of information so that the programs can address the needs of countries.

From our own perspective there are two issues I would like to raise or reiterate. One (1) has to do with our own interest in developing vital registration. I think the ICE group is looking at when you have the data already, how do you process them quickly? We want to look at the two ends of the data production in vital registration. 2) We are very interested in data analysis and data dissemination, which are important. When we have produced so much data, I am sure our greatest interest is to have it made good use of so that the effort and resources put into generating the data are truly beneficial.

In conclusion, I would say that ICE has indeed made an important contribution in advancing the automation of mortality statistics. Judging from this group and the interest outside of this group, a lot of systems have benefited from its efforts, and a lot more could be influenced in this positive direction. We hope that somehow, an initiative like this might go on and that the burden NCHS now has will be shared internationally again. Perhaps this is also something that could be discussed.

Thank you.

Bedirhan Ustun, Panelist

Classification Assessment Surveys and Terminology Group, World Health Organization

My comments will refer basically to what we call the Family of International Classifications. When we herd the different members of international health classifications into a coherent set like Bill Gates' family of Microsoft products (although this is not a very popular analogy in the electronic tools community), we really want to have seamlessly integrated components of health information systems. Mortality is, of course, one of them. My presentation and thoughts for the future will refer to what we can learn from the ICE experience, and how we can contribute to the ICE experience so that it is a two-way contribution.

Let me tell you about the ICD that ICE focuses on. We take this as an international public good, and for those of you who do not know, ICD is 150 years old this year. It was in 1853 that the International Statistical Congress generated the ICD–1, so I think we should have made some sort of a big celebration because it is older than many states that I know. Anyway, over the years, it has become the international standard, and currently WHO has a mortality database in which exists data and mortality statistics for 110 countries; this constitutes 3,500-plus country-years in terms of mortality statistics. Thanks to that database, we can currently make international comparisons in terms of life expectancy and causes of death. Without ICD and ICE effort, this could have not been possible. With the international public good, there are basic conversion tables between different versions of ICD, and as Michael Chopin, the chair of the Electronic Tools Committee mentioned, we will soon provide the Internet version of ICD–10 and try to improve it as time goes on. Thinking of this as an international public good puts into perspective that we have a tool that will synthesize and distill information as basic knowledge to everyone globally. You as participants of the ICE meetings should feel responsible and proud of this.

My basic message is that yes, ICE has improved—and is still improving—mortality statistics worldwide in terms of better formulation, improved reliability, and refined terminology. I remember Harry Rosenberg saying in Australia that there was a saying in his office, ''If you are not dead, we are not interested.'' Of course, we are all interested in mortality, but we have to see how we can go beyond that to link this information, as part of a jigsaw puzzle, to a bigger picture. I think ICE is as a model platform to share knowledge and experience.

This meeting also serves as a ''systematic review'' of automation mechanisms. Now, I put ''systematic review'' into quotation marks because in this age, systematic review has become a science as well. I mean, the first day of the ICE meeting had some very good comprehensive review, but it was not systematic in terms of operational criteria, input, outputs, and so forth. Maybe we can generalize our review structure against certain criteria.

Then, of course, we have seen examples of electronic death registration, and we can certainly improve on that. In the age of electronic health records, we really need more electronic tools. Electronic death registration should not be seen as a stand-alone product; rather, it should be seen as a part of an overall comprehensive health information system in which registration has its own niche.

Of course, the language issue is a big one that came up here. I do not want to preach to the choir as an international community, but the issue of translation and linking up of terminologies in electronic dictionaries is an important one. I think the technology today is a good guide for us as to how to successfully implement this. We have been shown some of the pitfalls, such as in the German language, translating the Index, and so forth.

Training is another important issue, and I know that we are coming from different backgrounds across several disciplines. However, maybe we can go beyond our disciplinary perspective because it may give us tunnel vision. Of course, nosology is a very important science, as taxonomy, and a profession that performs important tasks. But can we possibly create a meta-skill out of this, a nosology skill? This is a know-how that can be formulated operationally, and then we can disseminate or transmit it in a better way because we cannot generate nosologists in developing countries per se. We really have to understand the core or essence of the matter, and then transmit that know-how to the developing countries if you want to disseminate this information.

In terms of implementation, ICE has made a big improvement in terms of networking with the WHO Mortality Forum, Mortality Reference Group, and so forth.

I think in terms of quality assurance mechanisms, quality assurance is becoming another procedural product. You could probably call that ''systematic reviewers.'' There are certain steps in terms of quality assurance, and I think we can, in the future, have a more in-depth approach to quality assurance for mortality data.

Currently, we have 110 countries implementing ICD with ICD–10, ICD–9, or even ICD–8 in some cases. However, there are 81 countries that have not implemented it yet. WHO's Implementation Committee said that implementation of ICD, at least in mortality, should be a priority. Before 2010, we should have full coverage. The sooner we achieve that, the better, so we should not be content by the vertical height that we have reached with our eyes. Rather, we should horizontally disseminate that worldwide because the information gap is embarrassing. I was looking at a slide that showed the world from a satellite during the night; as you can imagine, all the seas glow by light. I think it was a good parallel to the information content of the mortality statistics because all of the Northern Hemisphere, the U.S., Canada, and Europe, were bright during the night whereas Africa was all in the dark. This is an information paradox.

Today, much of human mortality is in Africa, yet the least data is in Africa, and that should be addressed.

When WHO made the ICD–10 and published it in 1990, it was promised that the interval between revisions should be ten years, so by 2000 we should have come up with ICD–11. ICD–11 in 2000 became a ''model non grata,'' I would say, but we still have to think about an ICD–11. We cannot postpone it indefinitely. There should be an ICD–11.

The issue of coding SARS came up in a previous session. I think ICD–11 should go beyond coding SARS and seeing all the mortality, that is, we should not only have a mortality perspective but also an illness or health-status perspective. These different perspectives should contribute in terms of how we can build ICD–11 guided by scientific principles, user needs, and better implementation infrastructure. This is because in as much as SARS is important today, there are only 100 deaths; however, there are millions of other deaths that we ignore, sadly, such as malaria, tuberculosis, etc. What I am saying is that we should really see what matters; 20 percent of ICD codes should be sufficient for developing countries to explain 90 percent of their mortality information.

International multidisciplinary participation and collaboration should be a model, of which ICE is a very good example. Our vision is to collect information globally at the source through validated tools and process them in a timely fashion. We hope to move to an electronic, online system soon; if they do it in banking, why can we not do it in health? That would be systematic information. Defining the elements, scope, and relation among different systems and organizing them into a good structure should be the future of ICE.

Let me reiterate a point I made earlier concerning the saying, ''If you are not dead, we are not interested.'' We are not only counting deaths. We should also focus on life and how ICE efforts could help the other elements of WHO's Family of Classifications because when you are alive, you have morbidity. I have heard that, for example, the MICAR has been given to the morbidity people but how that link or transposition is achieved is an important thing.

Where do we go from here? Einstein was told he had a learning disability in a Swiss school, the country that I come from, and he was almost expelled from the school. His principles are very straightforward: ''Out of clutter, find simplicity,'' ''From discord, find harmony,'' and ''In the middle of difficulty lies opportunity.''

I think ICE gives us that, and possibly we can have a better classification if we think of the periodic table and how they constructed it. It has a natural classification in itself that predicts how the elements would behave in certain chemical reactions. For the future of ICD–10, we should really look into the real nature of the diseases, not only how they are killing people, such as by pneumonia and so forth. SARS should be coded as a virus as they have identified the agent. That will be more important for us. The periodic table is like a data cube; there are many dimensions in the electronic shell structure so you can really see to that from different dimensions.

My message is that, yes, ICE has done a huge effort in terms of improving mortality statistics, and we have learned from it, not only from its products but also from the way it works. I would very much like to give the message to the other heads of collaborating centers that we have to be able to transpose what we have learned in ICE to other areas. We have to make the other areas more systematic and operational, and we want to have a more comprehensive health information system. If we do that, then generating an ICD–11 will not be a dreadful task because then we will see where it needs improvement and how we can maintain it. Every renovation, like the cherry blossoms, should be built in for renewing the system.

Thank you.

Gerard Pavillon, Panelist

National Institute of Health and Medical Research (INSERM), France

When I began to participate in international projects in 1993 with the WHO French Collaborating Center, this period was a turning point. Work on the new revision had just been finished, and ICD–10 was finally published. A lot of work had been done to issue this revision, and now it was time to use it. I remember that there was a paradoxical situation. Some countries, such as Denmark and Switzerland, implemented the ICD–10 immediately after its publication. Other countries did not know where to go, and there were a lot of questions and issues. The main problem was one of expertise. The implementation of a new revision needs high-level coders for training and assessment, and also to adapt automated coding systems.

Between 1993 and 1996, some important events took place. At the international level, the ICE on automated coding systems was launched, and the first plenary meeting was in 1996. At the same time, Eurostat, the European Statistic Department, started important projects on mortality data. Of course, there were questions concerning ICD–10 implementation, data quality, and international comparability.

What about the ICE work since 1996? Three plenary meetings with important international participation have been organized. The proceedings of the first two plenary meetings have been published, and this is essential. For those who worked on these two volumes, I know they did a huge job, but now the volumes are references for what has been done. Along this line, if the proceedings of this meeting are published, I would propose to include the paper from Harry Rosenberg entitled, ''Approach to Implementing ICD–10 for Vital Statistics.'' Harry has years of experience both in mortality statistics and in international collaboration. This paper includes important facts and ideas, and it should find its place in this session.

What else has been done in the ICE? The recommendations defined in the first plenary meeting were decisive: for instance the Mortality Forum in English and Spanish and the Mortality Reference Group are derived from these recommendations.

There were many suggestions in plenary meetings. The fact that the U.N., WHO, WHO Collaborating Centers, Pan America Health Organization (PAHO), and Eurostat have been participating in the ICE meetings will allow achieving a common goal: to generalize ICD–10 implementation with a high level of data quality and comparability.

Where are we now? There are extensive international projects on the implementation and update of ICD–10 and on coding problems. ACME is now an international standard for the selection of the underlying cause; however, there remain a lot of things to do to facilitate the implementation of international coding systems, especially at the language level. Moreover, we saw in this session that electronic certification and data dissemination systems are developing or changing a lot according to technology development. Thus, there is still a lot of work to do if we want to achieve the goal of international comparability.

My conclusion is that the ICE is a natural place for international collaboration. This is the place where the U.N., WHO, PAHO, Eurostat, and users from many different countries can share experiences and ideas and start new projects.

Thank you.

Discussion on Presentations of Session 11

L. GERAN: I have two comments. One (1) is about the development of information systems throughout the world. I am drawing an example of international cooperation that we have in Statistics Canada where we are helping Ethiopians do a census. What has happened is that, through our work, the Ethiopians have ''leapfrogged'' a data development stage; they actually have state-of-the-art geographic information systems now, which are kind of the envy of everybody. So I think there are lots of opportunities to bring systems to the developing world. That was an example of developing nations working with experts in other countries. Hopefully, those sorts of models can be applied from censuses and surveys and brought into the health and mortality area.

The second thing (2) is that everyone comes away from an ICE meeting really excited but kind of depressed about all the work we have to do when we go home. Now, my director has said, ''Do a coroner's database. Do a physician-education system through universities. Do another one for existing physicians and coroners. By the way, you still have your regular work to do to get the national statistics out. Do the comparability studies, and in your spare time do some international work. And what about that multiple-cost system you promised?'' I think some work at the ICE can be done to give some direction about the relative priorities, the order in which these things should be done. As I see it, I am not going to produce a multiple-cause database until our physician training increases the number and quality of conditions on the death certificate. Any suggestions about relative priorities, especially in relation to developing countries, would be welcome.

S. WALKER: Sue Walker from Australia. I come from a country that uses the MMDS, but a lot of my work is with developing countries, training mortality coders and morbidity coders. A lot of the coders in some of the countries in which I have worked are not supported. They are not medical officers and they are not very familiar with the concepts of medicine; it seems to me we should be able to use a set of decision tables similar to those that are valuable in the MMDS to allow the coders to make standardized decisions on underlying cause. I think that would help us to improve the comparability between countries that use automated systems and those that do not yet have the infrastructure to allow the automated systems to be used. I would be interested to know if anybody thinks that is a useful idea and whether it would be possible to do something like that.

S. NOTZON: I think it is nice to be reminded that there is more to the world than just our respective countries. We are really sort of a developed-country club here, if you will. By default, these are the countries that have the good-quality vital statistics; they also have the resources, the revenue, to develop or even to contemplate an automated system. It is important not to forget about the rest of the world, and I thank all of the people who have reminded us of that.

G. PAVILLON: Just on this aspect of helping some countries to produce mortality statistics. I have experience with North Africa, Tunisia mainly. This year, Tunisia produced for the first time mortality statistics. Our experience is that automatic coding systems are helping a lot for that, but I think that the main thing needed is training and expertise. I think that it would be important to try to organize such training sessions on the general aspect of how to create and implement a mortality information system and a civil registration system to produce multilevel statistics.

B. USTUN: I think, following up Gerard Pavillon's points and in response to Leslie Geran's question, that the issue of health information systems should be seen as a comprehensive topic that has different rubrics of information. The right of mortality registration is one of them. I think it is exemplary to have developing countries coupled or ''sistering'' with other countries.

An alternative approach that I will propose is that we cannot have an international multilateral collaboration in a network fashion yet still have some agreed-upon plan in terms of what will constitute a basic health information system for all countries, developed or developing, so that we have a common denominator. Rather than let a thousand flowers bloom in their own natural way, we can have a proactive approach: put ACME MICAR in a box, and this should be ICD–10, and this box of know-how should penetrate everywhere. That is what I meant by horizontal dissemination. When that product travels to a target, finds the interlocutor in that country, and fills a niche for vital registration, it will blossom. That is the proposal, namely, that we should create a product, together with the Heads of Collaborating Centers, so that we have something that will function like a turnkey application. I know nothing is that simple and perfect, but I think that might be our goal. I would suggest that rather than doing it one by one, try to have a generic solution that we can tailor as we go along. Thank you.

S. NOTZON: I have been talking with some members of the ICE Planning Group about the idea of developing a toolbox or a step-by-step approach to implementing an automated coding system, how best to start, and what steps should follow in sequence. Basically, we would learn from the mistakes that all of the countries that have implemented automated systems have made in the process of developing those systems.

A. MIMIMBA: I would like to thank the panelists and all the committees that meet about assisting developing countries to come up to speed. I think that is very important, especially in some countries in Sub-Saharan Africa, where there is a sharp increase in deaths due to HIV/AIDS. All the classical demonstrate large records to network. They have been developed so that those countries can actually develop a registration system that will inform on the magnitude of HIV, etc. In such countries, rather than improving the data registration throughout the country, a sample of deaths can be taken. We have seen that that also works.

Another idea is the ID system. In all these countries, there are national ID numbers, so some efforts can be made to convert those into some kind of pattern for the vital registration system; it can yield ready statistics. Thank you very much.

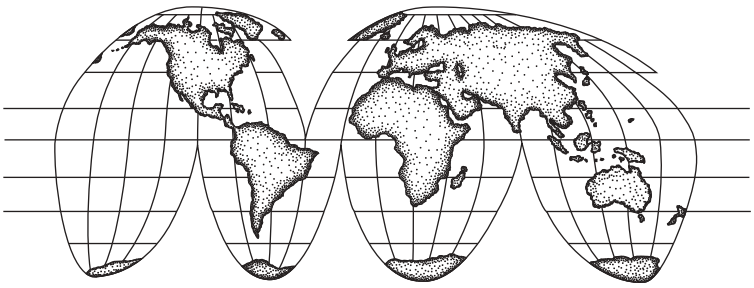
S. NOTZON: A subtopic that has been part of several Heads of Centers meetings and of discussions among the ICE Planning Group is the notion of creating or resurrecting an organization to promote the improvement of civil registration in countries. We have been discussing this on a fairly regular basis now with the U.N. Statistics Division, and we have raised the issue with WHO as well. The problem seems to be finding a funding source, and we are certainly working on that.

I have a couple of other comments regarding some of the remarks that Bedirhan Ustun made. First (1), he mentioned the mortality database that WHO has on its Web site, and I compliment him on that. I think it is a terrific source of information, and I am very pleased to see that now not only is there information for deaths and population denominators, but also measures of the completeness of registration in each of those countries. I could quibble with your measures of completeness, but nonetheless, I think it is a valuable step to make people aware of the limitations or reliability of the information that is being provided.

Second (2), in regard to ICD–11, I would say that anybody in the audience who is over 50 years is hoping that ICD–11 will be on hold for at least 10 years so they will have retired by the time we have to implement it—okay, 20 years.

My thanks to the panelists, and to all of you, for coming.

Closing Remarks



Closing Remarks

Ed Sondik, PhD, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

First of all, I want to thank everyone involved in putting all of this together. While I did not hear most of the discussion, the reports I have been getting are that this has been among the best meetings (if not the best such meeting) in terms of the discussion, which has been very rich. There is a great deal of enthusiasm.

I was sorry to hear about the ICD–11. I envision that some day when we want to make changes in a coding system, it will be very straightforward for us to be able to do this, at least the minor changes, simply by downloading the appropriate instructions into everyone's computer and updating automatically. This is done in industry, in a variety of ways, all the time. Industry could not function if it were not for that capability. What we are talking about here, I think, is building the infrastructure in every country so that we are able to do that. We really are one world; we may have multiple languages, but we are really one world. The more we advance this idea, the more it will become feasible to do that type of thing.

I know that electronic death registration came up several times during the meeting. This is a very high priority for us in the United States. There is a lot of enthusiasm on the part of our partners in all of the 50 States, the District of Columbia, and the other 6 areas in which we collect vital information. We are looking forward to making progress on this type of registration in the future. I think it is just critical to building a system that meets the needs for quality and responsiveness.

Now, let me interject something that may not have come up yet. Maybe it is something that we could think of as a topic for the future. We recently held a meeting here, an international meeting, on the topic of summary measures of health. One of the themes of that meeting was that mortality is clearly one very significant component of health, but, of course, there is another component, namely, morbidity, wellness, and so forth. There is an effort in many countries to try to find the most appropriate set of measures to use that combine, in some way, mortality with morbidity or wellness. When you think about doing this, what comes very naturally to mind is to think not only of the mortality system and the birth system, but to think of the other systems that we have for collecting information on health. Think of them as welded or melded together.

The point that the gentleman from South Africa [Asood Mimimba] just made about using surveys in certain circumstances if we cannot get all data is very important. Obviously we want to aim toward complete registration, but we also have a series of decisions that we need to make now about surveys of mortality. I think part of our job is to think in those terms as well as developing the system. There may be ways that we can get the information that we need to make important decisions at the same time that we develop this system.

I would suggest that, in the future, this group also consider its relationship to the collection of other health-related information and how this can all be brought together in terms of using informatics to be as responsive to each country's decision makers and public as it can be.

What I hope we will do is keep you all informed on what is happening in these other areas, and perhaps these two areas can sometime down the road sort of merge together. What you are talking about, in my view, is the foundation for health statistics, but clearly it is not everything. I think we should try to have as broad a vision as possible of how we use information, how we need this information, and then how we actually use it.

Congratulations to everyone who organized this meeting, and thanks to you all for attending. It really is our pleasure to host this very important effort.

Thank you very much.

Closing Remarks

Dr. Robert N. Anderson, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

I have to say that when Bedirhan [Ustun] brought up ICD–11, I felt some rising panic because I have very little chance of being retired by the time that would have to be implemented.

Let me thank those who handled the details of this conference; without them, something like this just does not go well: Ken Kochanek, Ari Minino, Juan Albertorio, Pat Drummond, and the staff of Courtesy Associates.

It is clear to me from listening, in particular to the last panel, that we still have a lot of work to do in this effort. We need to continue our efforts to improve and refine our automated systems, and perhaps as Ron [Casey] mentioned earlier, we also need to work better as a unit to do so. I think that collaborative efforts should continue to be a top priority for this group. We also need to make our expertise and resources available, when possible, to those countries whose automated systems are in their infancy or to those who wish to implement automated systems, as Grace [Bediako] and Gerard [Pavillon] pointed out. International comparability should be a top priority because it does benefit us all.

In the Division of Vital Statistics and NCHS, we are committed to those efforts, and I personally look forward to continuing our collaboration with you all through the ICE.

Thank you for coming.

Closing Remarks

Dr. Sam Notzon, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

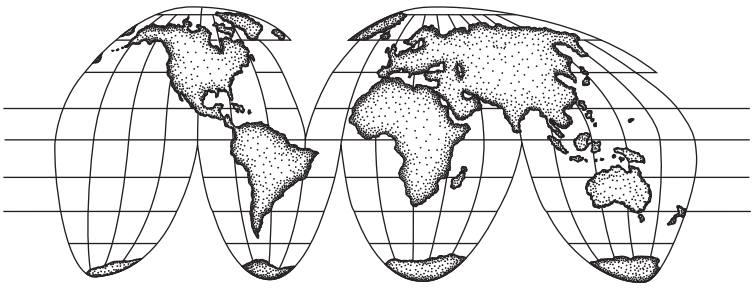
One thing I would like to mention is that I think it is fascinating to watch the MMDS system, something that was developed as a proprietary system for a single country, gradually evolve into an international good. This is really fascinating to observe from a sociological perspective. It is going to be a totally easy process, but I think it is inevitable. We are certainly moving in that direction, and we will keep doing so.

We talked in this last panel about future activities. There are some additional future activities that you have heard here: 1) the notion of a language-independent automated coding system and electronic death registration (EDR), and our efforts in many countries to move towards these goals; 2) the notion of implementing automated coding systems in a variety of countries, that is, spreading the gospel of automated coding; 3) we have also talked about our future collaboration with Eurostat and the focus on European countries. The focus on European activities will keep us busy, in addition to many of the other suggestions that have been made here. We thank you all for those.

Finally, although many people have thanked me for organizing this meeting, I believe the thanks should flow in the other direction. That is, I should thank all of you because, in a sense, my job is the easiest—I bring people together who are very capable, and they can take it from there.

I thank you all and declare this meeting closed.

Contributed Papers



Contributed Papers

1) Marchetti, Stephano, Monica Pace, Stefania Macchia and Luisa Frova. ‘‘ACS in Italy: Transition to ICD–10 Revision.’’

2) Rosenberg, Harry. ‘‘Approaches to Implementing ICD–10 for Vital Statistics.’’

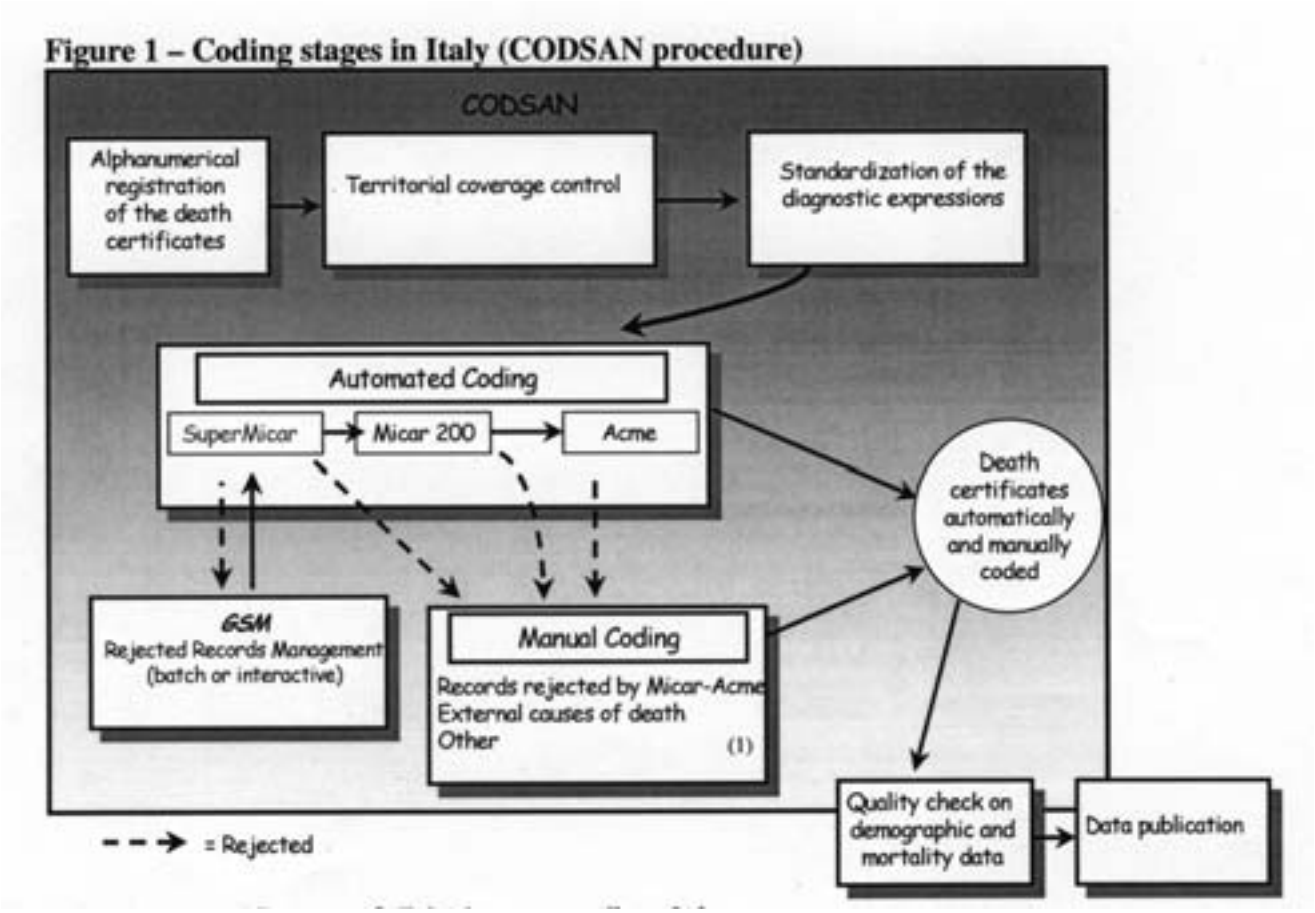
ACS in Italy: Transition to ICD–10 Revision

Stefano Marchetti, Monica Pace, Stefania Macchia and Luisa Frova
Italian National Institute of Statistics (ISTAT)

1. *Background*

Since 1995 ISTAT has been coding Causes of Death in ICD–10 revision by means of an integrated version, modified and adapted to the Italian language, of MICAR-ACME System (developed by NCHS). In particular, the software CODSAN has been developed to best exploit the potentials of automated coding. CODSAN allows to perform a series of qualitative and quantitative controls on material received, to manage an integrated flow of the files and to intervene in cases of rejected records from automated coding system (Figure 1).

Figure 1 – Coding stages in Italy (CODSAN procedure)



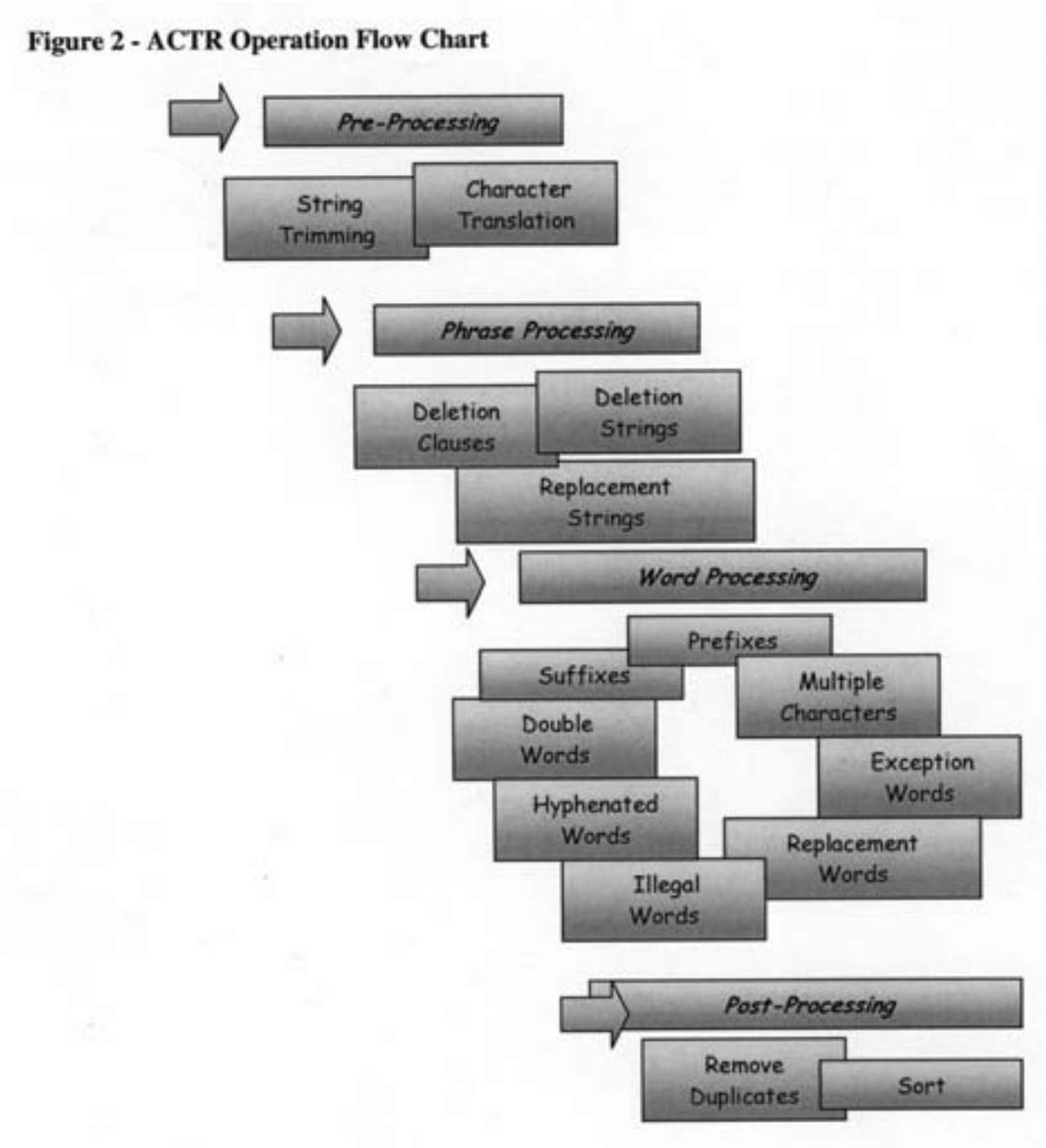
(1) Approximately 25 percent of all deaths are manually coded.

2. ACTR—Automated Coding by Text Recognition

With the implementation of ICD–10 revision Italy will still use NCHS software (obviously, the version for the new revision). In order to improve the performance of the coding system with the Italian language, standardization step and SuperMICAR will be substituted by **ACTR software** (Automated Coding by Text Recognition):

- **A fully generalized software** product not dependent on the classification and on the language adopted (is based on the methodology developed by U.S. Census Bureau and uses investigation and matching algorithm developed by researchers from Statistics Canada).
- Has been **used in several fields** (Censuses of Agriculture & Population; Health; Labor Force Survey; Business Register; Transportation; Tourism).
    - **Available on multiple platforms**
      Windows 95 and Windows NT;
      Unix (HP, SGI & SUN).
    - **Not Requirements**
      additional software purchases;
      royalties or executable fees;
      DBMS installation.
    - **Principles of Operation**
      Based on one or more ‘‘dictionaries’’ for text/code correlations;
      Complete and partial match capability;
      Robust and flexible parsing engine, both on dictionary and on death certificates. Parsing consists of standardizing text data with the aim to remove the grammatical or syntactic variability (irrelevant for coding purposes) that differentiates sentences with the same semantic could have. It comprises the following several steps in Figure 2:

Figure 2 - ACTR Operation Flow Chart



- Uses weighting algorithms
  - the string in input can match a string in the dictionary with an ‘‘exact match’’ (perfect correspondence between the strings) or with ‘‘partial match’’ (base on similar functions between the texts);
  - in partial match weights are inversely related to word frequencies in the dictionary.

3. The Dictionary

The dictionary used by ACTR has an important impact on the coding performance. It should be, as far as possible, reliable and exhaustive. The dictionary for coding is usually an expanded version of the official classification manual and must be developed in such a way as to approach the language of these manuals to that used by responders and to be able to be processed by software.

The dictionary utilized by ACTR to code medical terms is a revised version of the Italian BBD routinely used by SuperMICAR software. It has 187,000 medical terms or diagnostic entities (external causes are excluded) grouped by 100,000 ERNs (Entity Reference Numbers).

Words in ACTR dictionary must be separated whit blank spaces while the Italian ICD–IX BBD has each diagnostic entity without blanks between words. Therefore, a preliminary work has been done on BBD to separate with blank spaces most of the diagnostic entities.

4. Testing results

To assess the reliability of ACTR, a sample of 148,798 medical terms (about 40,000 death certificates) has been processed by the system. An iterative parsing strategy and several improvements on the BBD have been done.

Only ''exact matches'' have been accepted:

- in ACTR the extent of similarity between the strings is set up starting from the ''informational'' degree of the individual words;
- the ''informational'' degree of a word is inversely proportional to the frequency with which the words is found in the dictionary;
- in our context, the assumption that a word is less ''discriminatory'' more it is used, is not really suitable. Actually, words frequently used are often very important.

In the several attempts performed the principal results have been:

- The percentage of diagnostic expressions coded by ACTR steadily increases from 35 percent to 92 percent (Figure 3);
- The percentage of death certificates coded by ACTR steadily increases from 4 percent to 78 percent (Figure 4);
- In the last attempts, most of the records rejected are *redundant* (two identical texts with same ERN: due to a redundancy in the Italian BBD or as a consequence of parsing procedures) (Figure 5);
- Moreover, 8300 out of 9,000 *incoherent* records (two identical texts linked to different ERNs due to an error in the Italian BBD or as a consequence of parsing procedures) can be considered as redundant at ICD level because in some cases several ERN codes are linked to the same ICD code (Figure 5).

Figure 3 - Percentage of diagnostic expressions coded by ACTR

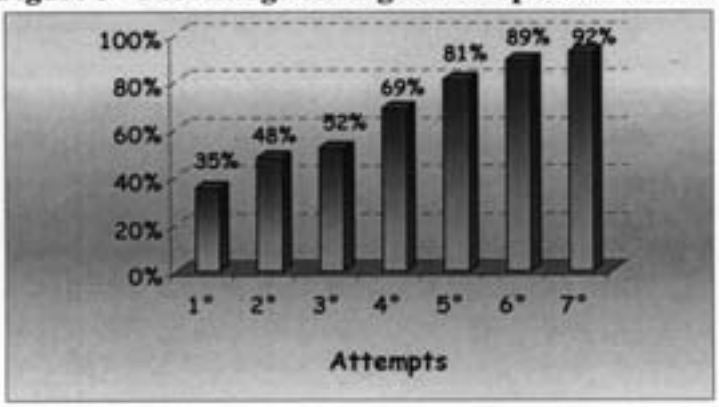


Figure 4 - Percentage of death certificates coded by ACTR

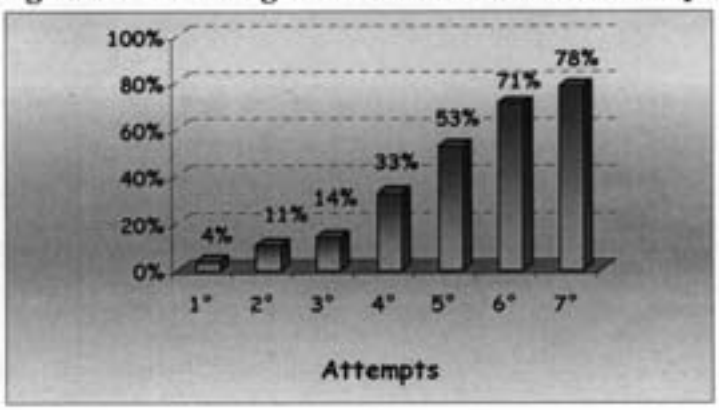
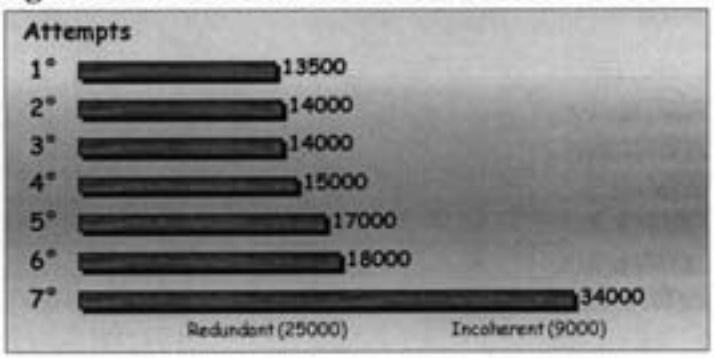


Figure 5 - Incoherent or redundant records of BBD rejected by ACTR



5. Conclusions

Applying ACTR to diagnostic expressions coding resulted to be a positive experience in Italy because:

- ACTR resulted to be flexible and easy to use.
- The strength of ACTR is the possibility of controlling and adapting each step of the parsing strategy.
- After preliminary attempts with low matching scores, the 92 percent of overall medical terms have been

automatically coded. This percentage (3 percent lower to the one performed by SuperMICAR) can be considered an excellent preliminary result. Actually, not all the potentialities of the ACTR software have been exploited yet, and moreover, the optimization of the dictionary (BBD) is still a work in progress: managing the parsing strategy is crucial in order to achieve optimal coding results with ACTR.

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Acknowledgements:

The authors would like to thank NCHS (USA), Statistics Canada and the colleagues of the Mortality Unit and of the Automated Coding Unit (ISTAT, Italy).

Approaches to Implementing ICD–10 for Vital Statistics

Harry M. Rosenberg, Ph.D.[1]
Consultant to the National Center for Health Statistics
Centers for Disease Control and Prevention

INTRODUCTION

Two major forces shaping the ICD in relation to mortality and vital statistics; one is the shifting emphasis of the ICD process and content from statistical to nonstatistical applications; and the other is the impact of automation. Understanding these two forces may help us better appreciate the present status of ICD, and may help us prepare for future challenges.

In this invitational presentation, Marjorie Greenberg, Head of the North American Collaborating Center, asked me if I would make some global observations on mortality and ICD, and also asked if I could draw some lessons and make some recommendations based on my experience in mortality statistics at the U.S. National Center for Health Statistics (NCHS) and on my work with the World Health Organization (WHO). This paper, therefore, begins with my observations on the larger changes affecting ICD from the perspective of mortality statistics, and then, more personally, presents lessons and recommendations based on my experience in mortality statistics.

- Context affecting ICD and mortality statistics
  Shift from statistical to nonstatistical applications of ICD
  Impact of automation
- Activities
  Mortality Reference Group (MRG)
  International Collaborative Effort on Automating Mortality Statistics (ICE)
  Future of automation of mortality statistics
  The U.S. experience in implementing ICD–10 for mortality
  Training
  International technical assistance
- Concluding observations and recommendations

CONTEXT: SHIFT FROM STATISTICAL TO NONSTATISTICAL APPLICATIONS OF ICD

A major change has occurred in the forces shaping ICD during the past 50 years: this is the shifting balance from statistical to non-statistical applications of the classification. At the beginning of the Century, ICD was devoted to mortality statistics applications; indeed, Bertillon's classification was called the ''International List of Causes of Death.''[2] Early interest in epidemic surveillance and disease patterns relied on death records, which were an available data source as early as the seventeenth century. To be sure there was early interest in lists that could be used to compile statistics on illness, but the main impetus in developing the early classifications was mortality. This began to change in the 1940s. During World War II and immediately thereafter, the ICD and some other classification systems were being developed for indexing hospital records.[3] For hospital records indexing, ICD was not sufficiently detailed; so special adaptations were developed in the U.S. and other countries that were more suitable for nonstatistical applications such as records indexing. In the U.S., the first major adaptation of ICD for hospital use was introduced during the Seventh Revision, and such adaptations have been issued decennially in concert with major ICD revisions as a related classification that preserves the structure of ICD, but is subject to its own updating and dissemination process. The latest U.S.

version is called the ''Clinical Modification'' of ICD–9[4] and is likely to be superceded by a Tenth Revision version in the future.[5] Countries other than the U.S., including Canada and Australia have also issued their own adaptations of ICD that are considered more suitable for non-statistical applications including medical indexing and medical billing.

Nonstatistical uses of ICD were given further impetus in the mid-1960s when the U.S. Government began subsidizing medical care for the elderly and indigent, through Medicare and Medicaid. The Clinical Modification provided highly suitable for a range of administrative functions associated with the new U.S. system of providing Federally subsidized medical care for the elderly and poor.

Nonstatistical uses of the ICD have impelled the great expansion in detail of the ICD. In the Sixth Revision (1948), the classification had only several hundred categories, but by the current Tenth Revision, the classification has expanded more than 10 times. Even with almost 8,000 categories, ICD–10 does not meet the nonstatistical classification needs of the U.S., so that the ICD–10 Clinical Modification in the U.S. will have about 50,000 codes, many times the number of codes in ICD–10.

The level of detail in ICD–10 is not generally relevant to mortality; causes of death are reported on death certificates in far less detail than on medical records. However, the high level of detail in ICD does not pose either coding or tabulation problems for mortality, because individual categories can be aggregated for mortality presentation and analysis. In contrast to the beginning of the Century when ICD was used principally for mortality classification, the non-statistical uses of ICD have clearly become dominant force dictating the content of ICD.

CONTEXT: IMPACT OF AUTOMATION

The second major force shaping the ICD environment is automation, or computer technology, as applied to data collection, classification, processing, and dissemination.[6,7] With respect to mortality, automation has profoundly affected virtually every aspect of operations and statistics. For example, for the past 30 years, manual mortality medical coding—an extremely labor intensive process by individuals based on knowledge and experience—has gradually been supplanted by automated systems in an increasing number of countries, initially in developed countries but now more and more in developing countries. Use of automated systems is increasing, because such systems produce higher quality, more consistent, and timelier data. Also, they produce both underlying and multiple cause data on a routine basis, which is not practical when causes of death are coded manually. While the shift to automation in mortality coding was initially inspired by the hope of cost savings, a hope that was not realized, automation did help ameliorate a growing problem for mortality—the dwindling availability of expert mortality coders, who were choosing other occupations with better compensation. The application of automation has indeed resulted in not only more and better data, but also in far more comparable data at the international level. Ultimately, cost savings for ongoing operations may be realized for some countries, but this is not likely for those developing, maintaining, and updating the software.

Automation is also having an impact on data dissemination at the national and international levels, and is beginning to have an impact on vital registration in those countries that are moving toward electronic registration of vital events.

Thus, two forces to keep in mind as we look at specific ICD activities related to mortality are the increasing emphasis on nonstatistical applications of ICD and the impact of automation. The first specific activity I will address is WHO's Mortality Reference Group.

MORTALITY REFERENCE GROUP

WHO's Mortality Reference Group (MRG) is the mechanism for initiating changes, clarifications, and corrections on mortality information in the ICD, as part of WHO's ICD updating process. Provisions for the MRG are described in two documents: the WHO long-term strategy document (WHO/HST/ICD/C/97.39) and

the Collaborating Centre Heads' Report for 1997 (WHO/HST/ICD/C/97.65). MRG's recommendations are forwarded to the Update Reference Committee (URC) for further review and action in a broader epidemiological and classificatory context.

Today, MRG is being shaped by both automation and the changing emphasis in ICD. Indeed, the MRG resulted in part from the International Collaborative Effort on Automating Mortality Statistics (ICE) about which I shall speak later and partly as a result of WHO's implementation of an ICD updating process—a process stimulated largely by the requirements of health care systems. Further, the MRG operates largely through electronic communications and through an electronic forum. The MRG is more important than ever to the ICD process for several reasons:

- the concept of the underlying cause of death
- the locus of mortality expertise
- the impact of automation on mortality coding
- the continuing importance of cause-of-death statistics for measuring health status

Underlying Cause of Death

Mortality statisticians struggled with the concept of cause of death for at least 50 years before settling on a conceptually and operationally satisfactory solution, which we now call the ''underlying cause of death.'' The problem results from the ambiguity of the term ''cause of death.'' Do we mean the immediate cause of death, for example, pneumonia, or do we mean the influenza that precipitated the pneumonia? The ambiguity was recognized by Dr. William Farr, the nineteenth century biostatistician who, with Marc D'Espine, developed the earliest lists of causes of death.8 In an effort to clarify what is being sought as the cause of death for statistical purposes, a variety of terms have been used including ''primary cause of death,'' ''principal cause of death,'' etc. In the late 1940s, the international community finally reached agreement on a concept for cause of death that was reasonably unambiguous and suitable for statistical tabulation and analysis. That term, ''the underlying cause of death,'' is defined as the medical condition that set in motion the train of morbid events that led to death.9

Having developed the concept, two problems had to be solved to operationalize the underlying cause of death for statistical purposes. The first was to elicit from the certifying physician a clear statement of the morbid conditions that led to death listed in a sequence that reflects causality, that is, how one morbid condition led to another, and ultimately to death itself. The second problem was how to code death certificates when the physician reports more than one cause of death.

The first problem was addressed in the Sixth Revision by promulgating the International Certificate of Medical Cause of Death (Figure 1) as the international standard for death certificates in all countries. The international form, which is divided into Part I and Part II, asks in Part I for the causal sequence as one condition per line beginning with the immediate cause and ending with the initiating or underlying cause, with intermediate conditions in between. In Part II, the international form also asks the physician to report other significant conditions that contributed to death but were not in the causal sequence.

The second problem—that of correctly coding the underlying cause of death when more than one condition was reported—recognized as early at the initial version of ICD, also known as the Bertillon Classification, had been addressed over the years in various ways, including coding notes to the ICD and the use of manuals of ''joint causes'' to guide coders. Countries varied considerably in their approaches to selecting a single cause of death when more than one cause was reported.10 The problem was addressed by WHO—also in the Sixth Revision—by mandating use of an international set of coding rules to select the underlying cause of death when the physician reported more than one cause, which was likely given the format of the international certificate of cause of death.

Thus, the three central questions for mortality statistics were addressed with the landmark Sixth Revision—namely, the concept of the underlying cause of death, the format of the international death certificate, and the content of the international mortality coding rules. In addition, the WHO issued Regulations

No. 1 in the Sixth Revision making the international form and the coding rules mandatory among member nations, thereby laying the statistical and statutory foundation for internationally comparable mortality statistics.[11]

While the concept of the ''underlying cause of death'' has been widely accepted for coding and tabulating mortality statistics, we know that the concept still causes confusion and consternation in the medical community, and sometimes in the legal community. The confusion can be acute when the reported cause of death differs from the tabulated cause of death, the latter being the cause that was selected as the underlying cause by medical coders using the international rules. In ICD–10, WHO attempted to clarify mortality terminology by distinguishing between the ''underlying cause of death'' and a new term, the ''originating antecedent condition.'' This is a distinction that mortality medical coders and some statisticians familiar with mortality coding may understand, but is only a partial clarification. In the hope of further clarification, I propose a distinction between three terms: (a) the ''reported underlying cause of death,'' which is what the physician actually reported as the underlying cause on the lowest used line of Part I of the death certificate; (b) the ''originating antecedent condition,'' which represents the underlying cause resulting from the ICD selection rules, that is, the condition that the physician should have put on the lowest used line of Part I if he or she completed the certificate properly (The originating antecedent condition was known in earlier coding parlance as the ''tentative underlying cause of death''); and (c) the ''tabulated underlying cause of death,'' which is the cause of death that results from applying the international mortality coding rules—both the selection and the modification rules—to the conditions reported by the physician. Use of these three terms, hopefully, can help users understand that what the physician reports as the underlying cause of death even in a properly completed cause-of-death statement may differ from the underlying cause of death that is coded and used for publication and analysis. In the U.S., the reported underlying cause and the tabulated underlying cause are in agreement for about 80 percent of death certificates, according to a study by Green.[12]

My first recommendation to the WHO and the Heads of Centers, therefore, is as follows:

- *The MRG should clarify the concept of underlying cause of death by distinguishing between reported underlying cause of death, originating antecedent condition, and tabulated underlying cause of death.*

ICD standards for mortality statistics—the international death certificate form and the cause-of-death coding rules—are not used in all countries. In some countries without trained mortality medical coders what is published is simply the cause reported on the lowest used line of Part I of the death certificate, without application of the international coding rules. Other countries are not using the international certificate of cause of death. Yet other countries—including some developed countries—have redesigned death certificates with an inverted sequence, that is, with the underlying cause of death on the first line of the death certificate and the immediate cause on the bottom line. All of these countries are out of compliance with WHO regulations and their mortality statistics are not comparable with those of the countries that implement WHO standards for mortality statistics. It is important that WHO redouble its efforts to promote standards for the collection and processing of cause-of-death statistics to improve the comparability of international mortality statistics. The MRG can help WHO focus its efforts in this work, and encourage compliance with ICD standards.

WHO should redouble efforts to promote use of the international death certificate and the international coding rules for mortality.

Locus of Mortality Expertise

Because of increasing influence of nonstatistical considerations in the development of ICD, the MRG is important as WHO's embodiment of international mortality coding expertise. The MRG can serve as an international locus where the concept of the underlying cause of death is fully understood in terms of theory as well as practice.

- *Even if there were no official ICD updating process, WHO should support the MRG as the official international body of experts who can—in their deliberate, systematic, and informed manner—resolve*

important mortality coding questions. Further, because of the increasing ICD emphasis on nonstatistical applications of ICD, the MRG provides a critical presence, both substantively and symbolically, of those who use ICD for statistical and research purposes rather than for health and medical administration and medical billing and reimbursement.

Automated Mortality Coding

Another reason for the importance of the MRG is the impact of automation on mortality statistics. While dominant concerns of the MRG today are on coding, other issues are likely to arise as automation continues to shape the environment in which the physician reports cause of death in those countries that develop electronic death registration (EDR). In a fully developed EDR, the certifying physician will enter causes of death directly into a computer onto an image of the death certificate; no paper copy should be necessary. As part of the physician's interaction with the computer, he or she can receive assistance in completing the death certificate by means of prompts, queries, and even tutorials; and thereby the physician can learn how to properly complete the medical certification of death, which, to now, has been a persistent challenge.

However, automation applied to cause-of-death registration poses challenges that the MRG needs to monitor: one of these is who completes the medical certification of death. In ICD, WHO strongly recommends that physicians complete the statement of cause of death. However, there is a danger that with the advent of electronic systems, it will be easy and convenient in a hospital setting for medical records staff—who now do data entry into hospital medical information systems—also to be asked to complete cause-of-death statements, possibly drawing from information on medical records. I witnessed this possibility in one of the prototype electronic death registration systems that I visited, where computer terminals for cause-of-death reporting on death certificates were situated in the medical records section of the hospital rather than in a setting closer to the practicing physicians. One of the risks here for mortality statistics is that medical records staff may lack information on the underlying cause of death that is known to the physician but may not appear on the hospital medical record. Another disadvantage is that medical records staff may not be able to benefit as physicians would from functionalities built into an electronic death registration system such as queries and tutorials.

Another potential pitfall of unfettered application of computer technology to death registration and mortality statistics is the uncritical use of predetermined lists—called ''pick lists''—from which a system user selects answers. Pick lists are widely used in electronic questionnaires and forms, so it is not surprising that energetic software developers have incorporated such lists into hospital information systems and could be included in EDRs. However, the software developers could not be expected to be aware of the potentially damaging impact of such lists on mortality data precision and accuracy. The danger of pick lists for mortality statistics is that predetermined lists may limit the physician's choices in reporting cause of death. Further, predetermined lists of medical conditions may be static over time, thus failing to reflect the dynamism of medical advances and resultant changes in medical terminology. As its resources allow, the MRG should be aware of EDR developments challenge those that may compromise the quality and comparability of cause-of-death statistics. In keeping with ICD, the medical certification of death should be the physician's own assessment of cause of death using his or her best diagnostic skills and best medical terminology. Otherwise, ICD will be unable to adapt to rapid changes in diagnosis and medical terminology, and to the emergence of new diseases like AIDS.

- MRG and the WHO Electronic Tools Committee should monitor developments in electronic death registration, such as who certifies cause of death and the use of lists to select cause of death, to ensure that inappropriate practices and technology do not result in poorer quality cause-of-death information.

Measuring Health Status

The MRG will be essential as long as cause-of-death statistics are a key international indicator of health status, as they have been for at least two centuries, and continue to be.[13] Currently, cause-of-death statistics are

essential to setting health goals using quantitative targets, a strategy used in an increasing number of countries. For example, health goals for the U.S. are spelled out in the document *Healthy People 2010*, which includes a total of 467 measurable health objectives. Of these, 59 are measured entirely in terms of cause-of-death statistics (See http://www.cdc.gov/nchs/hphome.htm.) In the international setting, comparable cause-of-death statistics are essential to comparative assessments of health status; thus, cause-of-death statistics are a key indicator in the recent *WHO World Health Report: Health Systems: Improving Performance* (See Annex Table 3, ''Deaths by cause, sex and mortality stratum in WHO Regions, estimates for 1999.'')[14] The MRG is essential to ensure that cause-of-death statistics are as comparable as possible among countries through adherence to the international standards embodied in ICD.

A Role for WHO. As the essential mortality input to the WHO Update Reference Committee (URC), the MRG is an integral component of WHO's ICD updating process; the process at the working group and Centre Heads level has been highly productive, as reflected by the many recommendations for updating, correcting, and improving ICD since the update process commenced five years ago. Both the MRG and the URC members, and their supporting Collaborating Centres, have invested enormous resources and effort to develop a successful mechanism that makes ICD relevant to the changing classification needs of health statistics, health care, and research. However, the updating process is not complete until WHO translates the approved changes into the reality of an updated ICD. To date, WHO efforts in this regard do not appear to be commensurate with those of the URC and the Collaborating Centres. As the steward of ICD, WHO should make concerted efforts to incorporate and disseminate approved updates to ICD and resources should be provided to adequately support this activity. If WHO is unable support the updating process because of resources constraints, WHO should seriously consider alternatives, as recommended by Rosemary Roberts and others at the 2001 Centre Heads meeting.[15]

- *WHO should make concerted efforts to incorporate updates into ICD and to rapidly disseminate the updated ICD. If this is not feasible, WHO should explore alternatives such as delegating certain dissemination responsibilities to Collaborating Centers.*

INTERNATIONAL COLLABORATIVE EFFORT ON AUTOMATING MORTALITY STATISTICS

Reflecting the impact of automation on ICD is the U.S. International Collaborative Effort on Automating Mortality Statistics (ICE). In describing the mortality ICE, we cover the following topics:

- Background
- NCHS international collaborative efforts
- First mortality ICE
- Institutional impact of the first ICE
- Second mortality ICE

Background

In the U.S., work on automating cause-of-death coding began in the late 1960s with the goal of producing higher quality mortality data, at lower cost. Introduction of the ''ACME'' software beginning with data year 1968 did result in higher quality and more consistent cause-of-death data, as well as multiple cause-of-death data; but not in reduced costs. Thus, our experience was that automated systems cost more and could only be justified on the basis of more and better mortality statistics.

Other countries, facing the same issues that motivated the creation of ACME, were also considering automating mortality medical coding by either adopting the U.S. system, or by creating their own systems, especially ''front-end'' systems for data entry. Considerable innovation along these lines occurred in Sweden with the development of MIKADO by Lars Age Johansson; in France, where Gerard Pavillon developed STYX; in England, which developed TRACER; and in Catalonia, where Gloria Perez-Albarracin and her colleagues developed a ''neural networks'' approach.[16] NCHS was aware of and in some cases collaborated in developing these systems.

By 1993, international activity in automation applied to mortality was widespread, creative, and vigorous. Enthusiasm was high contributing to an increase in requests to NCHS for international technical assistance and collaboration. Because the demand for NCHS involvement occurred at the same time as NCHS was attempting to implement ICD–10, inordinate pressures were placed on our staff. NCHS mortality medical coding was faced with the competing demands of international technical assistance to install and maintain ACME, of implementing ICD–10, and of keeping current on production of national mortality statistics. Fortunately, our counterparts in other countries volunteered their assistance, and NCHS gratefully accepted assistance from England, Sweden, Scotland, and France, who assisted in updating decision tables from ICD–9 to ICD–10 (Decision tables, which are available to all countries, as part of the NCHS mortality documentation, show acceptable causal relationships between two medical entities, and also embody the ICD's mortality coding ''modification'' rules. See http://www.cdc.gov/nchs/about/major/dvs/im.htm.)

To bring some order to the proliferation of requests for international involvement in automated systems, in 1994 NCHS considered creating an international forum in which automation of mortality statistics could be discussed. There were many common interests in mortality automation as well as concerns that generated widespread interest in establishing an international forum on this topic. One almost ubiquitous concern among countries was how to address the diminishing number of expert mortality medical coders, which was both a cause and a consequence of mortality automation. Another concern was how to channel and organize international inputs into the maintenance and updating of the ACME system. Other issues included developing alternatives to the U.S. SuperMICAR, which is the front end of the system that allows data entry of natural language rather than of codes. Enthusiasm for international collaboration and consensus on a multiplicity of candidate topics lent themselves to developing an agenda for the first meeting on mortality automation. NCHS considered it crucial to ensure the involvement of WHO, so that results of the meeting would support ICD.

NCHS International Collaborative Efforts

A precedent had already been established for NCHS-sponsored international forums thus providing the institutional structure for the first mortality ICE meeting. In the early 1980s the first NCHS International Collaborative Effort (called ''ICE'' by NCHS) focused on perinatal mortality, followed soon thereafter by an ICE on aging, and ICE on injury. An ICE on automating mortality statistics would be somewhat different from the other ICE's in that the focus would not be on research, but rather on collaboration to establish common approaches to the use of automation for mortality statistics.

First Mortality ICE

The first mortality ICE was held in Washington on November 12–15, 1996. Its stated purposes were: (1) to share knowledge and experience of automated systems for coding mortality information, (2) to develop and improve existing automated systems through international collaboration, (3) to facilitate the transition to ICD–10 for mortality, and (4) to establish mechanisms for technical support of automated systems. A total of 70 participants from 19 countries attended. The U.S. Agency for International Development provided support for selected international travel, as did the NCHS, through the U.S. Department of Health and Human Services' Office of International Health. While there were formal sessions, contributed papers and demonstrations of software, much of the activity occurred in facilitated discussion groups focused on specific topics including the following:

- Nosology and the training of nosologists
- Training for pc support and training system users
- System specifications, decision tables, mechanisms for updating decision tables, and quality control
- Bridge coding
- Data editing and querying
- External causes of death
- Language issues
- Implementation issues

Institutional Impact of the First Mortality ICE

A total of 47 recommendations were reported out in the final plenary session of the first ICE meeting. The recommendations were designed to move mortality automation forward within the context of the WHO framework, to promote mechanisms for communication, and to foster training and education oriented to automation. A number of the recommendations specified creation of new international mechanisms to implement action. Fortuitously, the WHO at the time was reinventing itself in terms of its modus operandi related to ICD. WHO was rationalizing its activities in terms of establishing long-range goals and an explicit work plan for ICD collaborating centres. The timing was suitable for implementing a number of the ICE recommendations within the framework of the WHO's ICD long-range plan. Accordingly, WHO established a number of working groups that reflected ICE recommendations. The subgroups include the following:

- The Mortality Forum—an international online discussion group of mortality coding problems, chaired by staff of the Nordic Collaborating Centre
- WHO's Mortality Reference Group, a group of mortality experts who review mortality coding and classification problems largely selected from the Mortality Forum and make recommendations to the WHO Update Reference Committee, the group that spans mortality and morbidity updating concerns. The Mortality Reference Group is now chaired by the Nordic Collaborating Centre, and the Update Reference Committee by the Australian Collaborating Centre.

- WHO's Electronic Tools Committee (ETC), a committee that is surveying the application of electronic systems to health classification, coding, and dissemination. The ETC is chaired by the German Institute for Medical Documentation and Information.
- WHO's Subgroup on Training and Credentialing, a group devoted to identifying training resources in support of ICD, for promoting standards and training for medical coders, and for elevating the stature of medical coders, in particular mortality medical coders and nosologists. The Subgroup is chaired by the North American Collaborating Centre.
- WHO's electronic bulletin board on mortality automation supported by the Australian Collaborating Centre
- A curriculum of mortality coding and related concepts oriented to automated coding conducted for international trainees by the North American Collaborating Centre, beginning 2001, and repeated in 2002.

After the first ICE meeting, an ICE steering committee held annual meetings to stay abreast of developments in mortality automation and to refine mechanisms for international collaboration on automation. The ICE steering committee developed a schema by which WHO sanctioned updates to ICD could quickly be incorporated into the ACME software. The steering committee also served as a sounding board and users' group for proposed modifications and improvements in the ACME and related software.

Second Mortality ICE

The second mortality ICE was held September 7–10, 1999, in Bethesda, Maryland. Both the geographic coverage and scope of the ICE expanded beyond that of the first ICE, and the format of the meeting was different. A total of 70 participants from 25 countries attended. Support for selected international travel was provided by the Soros Foundation and once again by the National Center for Health Statistics working with the DHHS Office of International Health. Once again, organizers of the ICE viewed their work as being within the framework of the WHO ICD process. The second meeting was organized into scientific sessions that dealt with many of the same topics as the first meeting but that reflected considerable maturation of the issues and methodologies. The scope of the topics was broader than that of the first meeting. While the first mortality ICE focused largely on automated coding, the second ICE also dealt with data dissemination issues and electronic death registration.

The next plenary mortality ICE is scheduled for April 7–10, 2003, in Washington, D.C. The agenda will build on the agenda of the Second Mortality ICE.

FUTURE OF AUTOMATING MORTALITY STATISTICS

Computer technology continues to evolve and diffuse into different domains, including ICD and vital statistics. Where are these developments likely to lead? I shall speculate on some immediate and longer-term developments as applied to mortality statistics in the following discussion:

- Automated Coding
- Data Retrieval
- Disseminating ICD
- Electronic Death Registration
- Impact on Mortality Trends
- Conclusion

Automated Coding

In terms of ICD as it applies to mortality statistics, where does automation go from here? The automated systems for mortality coding will certainly continue to be refined; for example, the proportion of death records that they will process completely will increase, so that the rejects will be a smaller and smaller proportion of

the total records processed. (Rejects are those records that cannot be processed automatically, and therefore have to be partially or completely manually processed.) Currently, a major problem area for automated coding are the external causes for which terminology tends to be in the almost unlimited vocabulary of the vernacular rather than in the relatively delimited terminology of medical conditions.

Second, refinements have to be made in the front-end systems, making them much more efficient. The ''neural network'' approach developed by Catalonia demonstrated that a dictionary of 4,600 natural language terms supported automated processing of about 90 percent of death records.[17] Developing the front end systems requires both resources and a high level of technical expertise in medical terminology, medical classification, and mortality coding, capabilities that are not abundant in the international arena. Initiatives need to be undertaken to assist countries without such resources to develop front end systems that use their medical languages, in combination with existing automated software. If the front-end systems are not developed, the countries can still use automated software for selecting the underlying cause of death but will require multiple cause data entry, which is labor intensive, costly, and as complex as manual coding of underlying cause of death. Without front end systems, some of the benefits of mortality automation are lost, including potential cost savings and detailed data retrieval (see below).

- Initiatives need to be undertaken to develop front end systems for use with computer programs like ACME and TRANSAX that automatically select the underlying cause of death and that produce multiple cause data. Front end systems like SuperMICAR not only reduce the cost and effort of data entry, but they also can yield highly detailed diagnostic information. WHO should support and encourage such efforts, since they will facilitate the wider adoption of automated systems that result in more comparable international mortality statistics.

Data Retrieval

Automated systems for mortality coding hold enormous potential for data retrieval. In the NCHS MICAR system, for example, conditions are coded in more detail than the ICD using what are called ''Entity Reference Numbers'' (ERN) to denote each medical condition, and the ERN's are subsequently converted into ICD codes. The ERN's themselves can be used for data retrieval. With SuperMICAR, the literal text on the death certificate is also retrievable. Thus, with effective front end systems, much more information can be retrieved than with ICD codes whose use sometimes results in a loss of diagnostic detail and nuance. With front end systems, the potential of reproducing the exact medical terminology used to describe cause of death can contribute to a better understanding styles of medical certification, to retrieving information on specific drugs now subsumed under broad terms, and to retrieving specific information on accidents and injuries that may be obscured in the broad categories of the ICD.

Disseminating ICD

Another frontier is in disseminating ICD electronically. Many issues are involved including the copyright prerogatives of WHO. It is imperative that a continuous updating process such as that now mandated by WHO, and implemented by the Mortality Reference Group and the Update Reference Committee, have an efficient dissemination mechanism. Printed text does not seem to be compatible with continuous updating. Electronic means of updating ICD and disseminating it, along the lines developed by Michael Schopen of the German Collaborating Centre, has great promise.[18]

Electronic Death Registration

One of the next major frontiers in automation is electronic vital registration.[19] In the U.S., electronic death registration (EDR) is still in a developmental phase, even though some states have online death

registration in a limited number of facilities (Additional information on the status of EDR in the U.S. is available at: http://www.naphsis.org). The issues of electronic vital registration are many, including, security, privacy, confidentiality, and standards for data capture and transmission.

EDR has great potential for improving the timeliness and accuracy of mortality medical information. Some view EDR as a virtual panacea for the persistent problem of training physicians on how to complete death certificates. With an EDR, one can build into the system prompts, edits, and tutorials, and basically train the physician online in how to certify cause of death properly. However, this advantage can only be realized if the physician actually completes the medical certification. While physician certification is strongly recommended by ICD and may be required by national or state law, it may be easy to circumvent in an electronic system. The physician could, for example, delegate completing the certificate to a secretary, to medical records staff, or to a data entry clerk, providing them with some type of electronic authorization or electronic signature that would imply that the certification was made by the physician rather than by a surrogate. Delegating the medical certification to nonmedical staff would not be unique to electronic systems; indeed, it is believed to occur to in existing systems with paper death certificates. However, with EDR, delegating the task of medical certification would be more unfortunate, because it would negate the potential benefits of improving the quality of cause-of-death information through the use online querying, instructions, and tutorials on how to complete death certificates.

A second potential pitfall of EDR is that those who design the EDR software may unwittingly make electronic certification too easy, indeed misleadingly easy, by providing physicians with a relatively brief list from which to choose diagnoses. This occurred in one hospital in the U.S., which developed a list of about 50 diagnoses from which the physician could choose cause of death. As mentioned earlier, this can result in a serious loss of diagnostic detail; it has the potential of undermining the dynamism of medical terminology; and it violates the idea that physicians should report using their own best diagnoses in their own words. Upon learning about the list developed for the hospital information system, NCHS expressed its objections in the strongest terms to the state registration official, and the practice was discontinued.

- *MRG and the Electronic Tools Committee should monitor developments in electronic death registration, such as who certifies cause of death and the use of lists to select cause of death, to ensure that inappropriate practices and technology do not result in poorer quality cause-of-death information.*

Impact on Mortality Trends

Continuing assessments have to be made of the impact of automation on data comparability over time. Numerous studies have been undertaken to assess the statistical impact of automated compared with manual systems.[20,21] Results of such studies are essential to interpret abrupt changes in trend that can result from changes in methodologies. Similar studies should accompany the advent if implementing electronic death registration systems, which are as likely to affect trend data as are changes in the format of paper death certificates.[22]

- Studies should be undertaken to assess the impact of automation on mortality statistics, including the effect of using electronic death registration.

Implications

Automation, thus, has the potential to enhance the quality and international comparability of mortality medical information coded according to the ICD. The wide adoption of ACME, endorsed most recently by EUROSTAT as a standard for the European Community, can improve the comparability of cause-of-death statistics, within the framework of the ICD.

THE U.S. EXPERIENCE IN IMPLEMENTING ICD–10 FOR MORTALITY

The U.S. implemented ICD–10 for mortality effective with deaths occurring in 1999. Work on ICD–10 began in 1992 and continues to the present, as NCHS still working on the second and final phase of the Comparability Study. The U.S. ICD–10 efforts, therefore, span a period of at least 10 years that include about 7 years when NCHS staff was augmented by contractors. Excluding the time and effort of NCHS staff, the contract costs are estimated to be on the order of at least $6 million. Two teams—geographically separated by several hundred miles—cooperated in the implementation: the mortality medical coding staff and computer systems staff in our Research Triangle Park facility in North Carolina and the statistics team in Hyattsville, Maryland.

Major Tasks

The main tasks involved in implementation were as follows:

- Converting the NCHS mortality coding software from ICD–9 to ICD–10
- Developing training materials for coders
- Preparing complete documentation of software
- Conducting the coding training courses for State coders
- Changing the software from DOS-based to WINDOWS applications
- Developing ICD–10 mortality tabulation lists, which provide cause-of-death table stubs
- Developing edits to ensure consistency between cause of death and age and sex, and other edits
- Preparing lists of rare causes that represent public health threats that must be queried
- Converting ICD–9 to ICD–10 query manuals for states to contact physicians regarding problematic certifications
- Redesigning all publications to accommodate new cause-of-death lists
- Designing and implementing a Comparability Study between ICD–9 and ICD–10
- Preparing two guides to states on how to implement a new revision, the first on needed steps and NCHS role, the second on using comparability ratios for analysis of trend data
- Conducting training courses for state statisticians on ICD–10 concepts and analysis, including coding rules, tabulation lists, ranking leading causes of death, multiple cause-of-death analysis, automated coding systems, use of comparability ratios, improving medical certification of death, and methods of quality assessment.

Role of the Internet

Implementation of ICD–10 for mortality in the U.S. was facilitated by development of the Internet. (See the NCHS mortality Web site at: http://www.cdc.gov/nchs/about/major/dvs/mortdata.htm.) When ICD–10 work began in the U.S. in 1992, e-mail had not yet been introduced; but by 1999, e-mail and the Internet were integral parts of our lives. During the decade of the 1990s desktop computers became increasingly fast and powerful, so that ultimately the NCHS mortality coding software could be run on a desktop. We were able to put many of our ICD–10 products, such as instruction manuals, guides to the States, and analytical publications on the Internet in a much more accessible and timely form than we could have if we had depended entirely on printed publications.

Lessons Learned

What lessons can we learn from the U.S. experience in implementing ICD–10?

Cost. The first is to recognize the great effort required to implement a new revision. The bulk of the work took us 7 years at a cost of at least $700,000 per year, for contract staff, excluding the cost of regular NCHS staff, in other words an estimate of at least $5 million dollars, plus almost $1 million for the Comparability Study. For a future major revision, might we expect to find the equivalent of $6 million for mortality implementation? Could we absorb the impact of another major revision given the other work of the national vital statistics system?

Program Impact. Another consideration in ICD–10 implementation was the impact on other work of our statistical center. When converting to a new revision, many other important tasks had to be given lower priority. But not everything else can be set aside as one has responsibility for maintaining ongoing data production. People do not stop dying during the ICD conversion period. Rather, death records continue to come in and have to be processed, edited, tabulated, analyzed, and published on a continuous basis. Thus, ICD implementation imposes not only financial cost but also stress on staff who have to implement the new revision while devoting sustained efforts to maintain current data production. The pressure on some individuals can be almost unbearable. Therefore, the Collaborating Centres and WHO have to be extremely cautious about considering a major revamping of the ICD.

Implications for the ICD Updating Process. The process I have described also has implications for the ICD updating process to which WHO and the Collaborating Centres have committed. While not as great as full implementation of a new revision, resources required by individual countries to incorporate ICD updates will nevertheless be considerable. Virtually all of the tasks identified for ICD–10 implementation have to be carried out for major ICD updates every 3–5 years.

- WHO, in contemplating future revisions, should consider the impact of major revisions on individual countries in terms of their costs of implementation and the impact of implementation on ongoing national statistical operations.

Mix of Skills. From the perspective of mortality, another lesson is the mix of skills required for ICD revision and updates: at least four broad types of skills are required: classification specialists or nosologists, statistician/demographer/analysts, programmers and systems analysts, and physician/epidemiologists. The mix of expertise is essential at the international and national levels, because ICD involves not only classification issues embodied in Volumes I and III, but also the definitions, statistical measures, tabulation lists, coding rules, and edits recommended in Volume II. Thus, classification specialists, physician/epidemiologists, and statisticians are essential partners in the ICD process, and systems analysts are needed when software has to be modified and redesigned.

- WHO, in contemplating future revisions, should consider the impact of major revisions on individual countries in terms of their costs of implementation and the impact of implementation on ongoing national statistical operations.

TRAINING

Training is a key element in the successful implementation of ICD. In the U.S., training is an essential and integral key component of the national vital statistics program—so important in fact that a regular curriculum of training is offered every year by NCHS in various aspects of vital statistics. One through 2-week courses are taught including the following subjects:

- Vital statistics measurement and production
- ICD–10 concepts and analysis
- Advanced mortality analysis
- Vital statistics administration
- Underlying and multiple cause-of-death coding
- PC Management

Because of the decentralized nature of the U.S. vital statistics system and because of the normal turnover in staff in the registration areas, we consider it essential that training opportunities be available to develop and maintain essential skills to successfully operate State vital statistics programs, and to contribute to a robust national data base. In addition, because of international interest in NCHS automation, we initiated a curriculum of coding, classification, and analysis oriented to international users. Last year, NCHS conducted its first 1-year long program in international training at our facility in North Carolina. Participants in the 2001 training were from Brazil, Egypt, Lithuania, Hong Kong, Hungary, Italy, South Africa, and Russia. In 2002, thus far, the countries have included Mauritius, Mexico, Kenya, Trinidad, and Mexico.

Changing Content

We have found that we cannot ''can'' our courses in ICD, that is, we cannot assume that a course will be valid and applicable for more than a year. Most courses are updated annually because of the dynamic nature of the vital statistics system. Most of our vital statistics instruction manuals—which document all our vital statistics operations and methodologies—are modified and updated annually to reflect changes in data collection methods and categories, changes in concepts and definitions, changes in medical diagnosis and terminology, and the emergence of new diseases and causes of injury.

Lessons Learned

What lessons have we learned from our training experience? First, that continuous training is essential for the operation of a successful national system. Second, that it is difficult to package a training program in static form in the face of the dynamism of the system. Third, that the best instructors are those directly involved in operations, production, and analysis, those who have to solve systems and data problems on an ongoing basis, and who are grounded in the realities of data collection, production, dissemination, evaluation, and analysis.

- ICD training packages have to be continuously updated. Trainers in ICD for vital statistics are best taken from those directly involved in national vital statistics operations, production, and data analysis.

A Role for WHO

At the international level, WHO can play an important role in training through its Geneva staff, regional staffs, and through the Subgroup on Training and Credentialing. WHO can promote and broker bilateral technical assistance and training arrangements, as well as identify available training resources and advertise bilateral and multilateral training opportunities, especially between countries with well-developed health statistics systems and countries that are making serious efforts to improve the quality and completeness of vital statistics data.

- WHO can play an important role by brokering bilateral technical assistance and training arrangements, and by using the Subgroup on Training and Credentialing to identify training resources.

INTERNATIONAL TECHNICAL ASSISTANCE

I was asked to comment on international technical assistance in mortality related to ICD. I shall cover the following topics:

- Background
- Jordan
- Egypt
- Jamaica
- Lessons Learned

Background

I was fortunate to have been called upon a number of times during the past few years to provide technical assistance in very different international settings. The experiences were challenging, gratifying, and interesting. During the past 3 years, I worked in Jordan, Egypt, and Jamaica. In Jordan I participated in a bilateral assistance program under the auspices of the U.S. Centers for Disease Control and Prevention with its counterpart CDC in Jordan. In Egypt I worked in a large scale project under the auspices of the U.S. Department of Health and Human Services' Office of International Health; and in Jamaica I provided technical assistance at the request of the Pan American Health Organization (PAHO) at the invitation of the Jamaican Government. In each request, assistance was being sought to strengthen mortality data systems, specifically to improve the coverage, the quality, and the timeliness of cause-of-death statistics. Our approach in undertaking these missions—and I was always accompanied by another staff member from NCHS and often a staff person from the host international organization or the host agency in the country—was to hold in-depth interviews with high-level officials in the key agencies, to follow-up with lower-level officials, and where possible to witness operations in the field.

While there were differences in the three countries in terms of organizational responsibilities and the extent of their problems, the similarities in both the problems and the proposed solutions are striking.

Jordan. Robert Anderson, Lead Statistician in the NCHS Mortality Statistics Branch, Division of Vital Statistics, and I made a technical assistance mission in July 2001 under the joint auspices of the U.S. and Jordanian Centers for Disease Control with the goal of making recommendations to improve the coverage and the quality of death registration, in particular cause of death. In Jordan, responsibility for vital registration was vested with the Ministry of Health, but processing was so slow that the security needs and demographic needs for the data were not being met. Accordingly, the Ministry of Interior, with responsibility for vital statistics as in many other countries, had the registration laws modified to require that death notifications be sent directly to it, with cursory emphasis on the cause-of-death information. We found that cause-of-death information, especially outside of metropolitan areas, was frequently provided by the family without medical attendance or input. We also found that the death notification forms used were not consistent with WHO guidelines. As in Egypt and other countries that had close medical relationships with the former Soviet Union, cause-of-death coding was done by physicians who had little or no training in ICD, little understanding of the cause-of-death coding rules, and little understanding of the concept of the underlying cause of death.

Our recommendations to the Jordanian Centers for Disease Control were (1) that coordination be established among the principal agencies that had a stake in vital registration, including births and infant deaths, and death statistics, namely, the Ministry of Interior, the Ministry of Health, and the Department of Statistics, (2) that Jordan adopt the International Form of the Medical Certificate of Cause of Death, and include a checkbox indicating where the certifying physician attended the death, (3) that cause of death coding not be done by physicians, but rather by specially trained mortality medical coders, and (4) that the Ministry of Health use the reported cause of death, rather than the coded cause of death—because these can differ due to the ICD coding rules, (5) that training in medical certification of cause of death be directed to three different groups—(a) new physicians, who have completed their internship, (b) experienced physicians and senior staff, and (3) nurses; most of these medical professionals worked for the Ministry of Health at least part-time, though there was also a large sector of private medical practice that could be reached with the assistance and support of the professional association of physicians. We emphasized that the cause-of-death training not be undertaken until the death notification forms were modified and brought into conformity with international standards.

(6) We recommended a process for improving cause-of-death statistics that would require coordination between the Ministry of Health and the Ministry of Interior. Basically, the Ministry of Health would provide a listing of deaths to the Ministry of Interior, which subsequently would provide detailed cause-of-death information that would replace the cursory information in the Ministry of Interior files and that would be the basis for official cause-of-death statistics. (7) We recommended that a set of pilot studies be conducted to determine the most practical and expeditious way to secure improved cause-of-death information, with the

pilot studies carried out in several health directorates to reflect a variety of environments, both urban and rural. (8) We recommended that the law make clear that the ultimate responsibility for the cause-of-death statement be vested in the certifying physician, who may have to be requested by the family from a local health office. The law should state that unless the certifying physician signs the death notification, an official death certificate cannot be issued. (9) We found that the vital statistics laws need to include a ''hold harmless'' provision for the certifying physician to ensure that he or she will not be subject to legal action because of statement of cause of death. Physicians need to assure the family of the decedent that the cause-of-death information is used for statistical purposes only, and that it is confidential information. (10) We recommended that local health districts query death certificates that are incomplete, that is, that local districts institute quality assessment programs to review cause-of-death statements for completeness and adequacy. (11) We recommended that the Ministry of Health begin publishing cause-of-death statistics as soon as possible.

Egypt. The technical assistance effort to improve mortality statistics in Egypt occurred in early 2001. From my vantage point the issues and solutions for Egypt were similar in many ways to those of Jordan, except that the institutional context was different. In Egypt, I was part of a large development team that was addressing a large number of areas, including water and sewer improvements, anti-smoking, perinatal and maternal health, and injury control. In each of these areas, the U.S. Department of Health and Human Services had identified experts, who had their counterparts in Egypt. Moreover, the technical assistance to Egypt was part of a long-standing and long-range program of cooperation between Egypt and the U.S., whereas the Jordanian effort was quite limited in scope, time, and resources between the U.S. CDC and the Jordanian CDC. From the statistics side, the members of the Egypt team were my colleague Dr. David Larson, an engineer with the NCHS Division of Health Examination Statistics who had previous experience in working with the statistical agencies in Egypt, and myself.

I found that for vital registration, the general situation in Egypt paralleled that of Jordan, reflecting once again the lasting influence of the Soviet relationships on medical and public health practice. Many physicians in both Jordan and Egypt received their medical training in the Soviet Union, so the issues to be addressed as well as the solutions in the two countries had many parallels. As in Jordan, we met with many high level officials concerned with registration and with health statistics. Among our recommendations were (1) that to the death notification form, which currently does conform to the WHO standards, instructions be added on how to complete the form. We recommended some changes in the form, in particular to collect more detailed information on injuries, and to collect demographic information that would be useful for statistical purposes and registration purposes. As in Jordan, the Ministry of the Interior, responsible for security matters, plays the dominant role in vital registration, and needs to establish a working relationship with the Ministry of Health and Population to support better cause-of-death statistics.

(2) Instructional materials are needed to help medical practitioners learn how to complete death certificates. We provided examples from the U.S. handbooks on medical certification, the U.S. plastic laminated sheets that have been distributed to thousands of physicians and hospitals throughout the U.S., examples of audio and visual aids, and training workbooks from the American College of Pathologists, which gave us permission to have this material translated into Arabic. (3) The vital statistics laws needed to be amended to support the death registration process, and to make clear that when deaths should be referred to medico-legal authorities. The law should make it illegal for anyone to modify the death certificate with the exception of the original certifying physician. (4) We recommended an extensive training program for physicians in several venues making the distinction, as in Jordan, between new physicians and those already involved in medical practice. For this, we spelled out the key components of a recommended training plan. (5) We made recommendations on the process for completing death certificates, and the role of the local health districts as well as the governates, which are higher administrative levels. (6) As in Jordan, we recommended that medical coding not be done by physicians—the old Soviet model—but rather at the governate level by trained medical coders, (7) we recommended establishing a team of expert coders and coding trainers, who could be trained in the U.S., and subsequently could train others in Egypt. (8) We recommended establishing a comprehensive quality control program that includes querying, quality control, and quality assessment at the

statistical level, and (9) we recommended upgrading vital statistics publications and analysis capabilities through training, by providing a course in vital statistics analysis in Cairo.

Jamaica. In September 2001, at the request of the PAHO, we provided technical assistance to the Government of Jamaica. The team consisted of the U.S. Director of Vital Statistics—Mary Anne Freedman—and me, as well as Margaret Hazelwood representing PAHO. As in other trips, we arranged meetings with high-level administrative staff and followed up with in-depth meetings with operations personnel and field visits. Jamaica was concerned about the degree of vital statistics coverage, the quality of cause-of-death statistics, the availability of its data base for analysis, and the capabilities of its analysts. In our final report, we made recommendations regarding improving vital statistics coverage, creating micro-data bases, improving cause-of-death reporting, improving cause-of-death coding, staff training, changing the vital statistics laws, and implementing revised vital certificates. Two subsequent trips were made to Jamaica at the request of PAHO. In January 2002, Brady Hamilton, a statistician with the NCHS Division of Vital Statistics, and I taught a 1-week course in vital statistics to staff of the Jamaica vital statistics program and the Ministry of Health, and this was followed in April 2002 by a technical assistance trip by Steve Steimel, one of the senior NCHS systems analysts, to provide assistance in developing the Jamaica vital statistics micro-database.

Lessons Learned

A number of lessons can be gleaned from our experience in providing international technical assistance in mortality related to ICD:

Improving Quality of Cause-of-Death Reporting. In every country that we visited the quality of cause-of-death statistics has been prominent concern. In some countries, only half the death certificates have cause-of-death information that can be considered substantively informative. For the other half, cause was listed as or equivalent to respiratory or cardiac arrest—terms that are totally uninformative from a medical or public health standpoint. So, training physicians is of critical importance if we are to have good national and international statistics on cause of death. We know that the quality of cause-of-death data depends entirely on how well the death certificate is completed, and this depends in turn on the ability of and the care with which the physician completes the medical certification of death.

Training physicians on how to complete death certificates needs to be tailored to the environments of different countries and to the way in which physicians in the respective countries are educated, and subsequently enter internships and residencies. Opportunities also exist for training physicians later in their medical careers through Continuing Medical Education programs in the U.S., or their equivalents in other countries. In addition, Internet-based resources are also available, including interactive tutorials.

- *Of paramount concern in many countries is the quality of cause-of-death reporting and the need for physician training in medical certification of death. Training physicians on how to complete death certificates needs to be tailored to the environments of different countries and to the way in which physicians in the respective countries are educated, and subsequently enter internships and residencies. Opportunities also exist for training physicians later in their medical careers through Continuing Medical Education programs in the U.S., or their equivalents in other countries. In addition, Internet-based resources are also available, including interactive tutorials. One such site is the mortality homepage of the U.S. National Center for Health Statistics at: http://www.cdc.gov/nchs/about/major/dvs/handbk.htm.*

WHO can play a valuable role by making member nations aware of existing resources to train physicians on how to complete the medical certification of cause of death.

WHO Can Monitor Quality. WHO can play an important role by monitoring data quality of countries, and by encouraging countries with data of poor quality to seek assistance and take steps to improve data. PAHO, for example, played a key role in encouraging Jamaica to seek outside assistance in improving the quality and completeness of vital statistics.

- *WHO should assess data quality, and encourage countries with data of poor quality to seek technical assistance, and should broker bilateral technical assistance and training. Bilateral arrangements have a number of distinct advantages.*

Involving Key Stakeholders. In the case of improving vital statistics, coordination and cooperation at the national and international levels is essential because three very different interest groups are involved: vital registration officials, health professionals, and census professionals; the need for this type of coordination was recognized as early as the Sixth Revision, and incorporated into the ICD work program.23/ Vital registration officials—sometimes tied in closely with the security apparatus of a nation—are interested principally in coverage issues; they want a record for every event—birth, death, marriage, dissolution of marriage, etc.; cause of death is of secondary interest, except when medico-legal investigation is involved. The second interest group is economists who are concerned with national economic policy and statistics, and national economic accounts. They, too, generally are interested principally in coverage issues, so that they can monitor the size of a national population and its growth. In contrast, the third group—health officials—want information that can be used for setting health goals and monitoring health progress in areas such as infectious diseases, chronic diseases, accidents, homicides, infant and maternal deaths. A fourth group—the national criminal justice system—needs information on deaths associated with violence, but often develops its own system of statistical surveillance based on police records.

Given the existence of these powerful national interest groups—security, economic development, and health—it is essential that the interest groups sit at the same table to achieve quality and completeness in national health statistics, because their interests should be seen as collective rather than as competitive and divisive. We sometimes see, however, that these interest groups do not recognize their common purposes, and may be highly critical of one another, thereby diminishing rather than enhancing their common purpose. I have seen situations in which officials from one agency refuse to meet with or speak to individuals of another agency, because of territorial concerns.

- WHO should encourage key stakeholders from different government sectors at the national level to recognize their mutual interest in good data.

What occurs at the national level provides object lessons at the international level, where our international statistical agency—the United Nations—and our international health agency—WHO—have a common interest in promoting good coverage and good quality in health statistics and vital statistics. An effort to forge such a relationship was made by NCHS's Marjorie Greenberg and Sam Notzon at last year's Centre Heads meeting, by sponsoring a session in which WHO and the UN statistical office could examine common issues. This should be encouraged by making such sessions a regular part of the Centre Heads meeting and by making this part of the WHO work plan for health statistics.

- *At the international level WHO and the UN should actively cooperate in promoting better quality data through development of cooperative strategies and supporting materials.*

Create an International Institute for Vital Registration and Statistics. There may be merit in encouraging the creation of an international nongovernmental group that promotes the common interests of vital registration, and provides an information exchange on best practices. For many years, the International Institute for Vital Registration and Statistics, supported with funds from private organizations and some U.S. federal agencies, served this function. That organization or an equivalent could encourage the development and maintenance of strong national vital statistics programs.

- *WHO and the UN should consider encouraging formation of an interest group that promotes the development of national registration programs.*

A Role for WHO as a Facilitator. Another lesson from our international experience is that international agencies such as WHO can provide an important role in promoting international technical assistance by

serving as facilitators of bilateral assistance, and by convening regional and international workshops on topics of common interest. PAHO has done an excellent job in this regard by identifying recipient and appropriate donor countries, so to speak, and by being a presence at all stages of technical assistance programs.

Advantages of Bilateral Assistance. I believe that the best technical assistance is bilateral assistance by countries that have on-going data systems. The donor countries are most familiar with state-of-the-art technologies, which change on a daily basis, and donor countries can provide a continuity of experience and a broad range of expertise from technical assistance to training.

- *WHO should assess data quality, and encourage countries with data of poor quality to seek technical assistance, and should broker bilateral technical assistance and training. Bilateral arrangements have a number of distinct advantages.*

Role of Training. Training is one of the most effective means of technical assistance. Training can be in classification, coding, database development, measurement, and analysis. In Jamaica we provided a week-long course in vital statistics measurement, ICD concepts, data production, and quality control that was well received, and could be made broadly available. However, the course cannot be ''canned'' into a static format, because we modify and update it annually as we do our coding training. In 2001, we began offering international training in cause-of-death coding oriented to automation, complemented with a data analysis component. NCHS will continue to offer the course to countries that are interested.

- *ICD training packages have to be continuously updated. Trainers in ICD for vital statistics are best taken from those directly involved in national vital statistics operations, production, and data analysis.*

CONCLUSION

To conclude, my remarks have attempted to integrate specific mortality activities in which I was involved with two major societal and institutional forces affecting ICD, namely, the shifting balance of ICD toward nonstatistical activities and the impact of automation on mortality statistics. It is evident that these two forces, which result from worldwide technological and institutional change, have major implications for ICD. While they create intense pressure to make ICD as current as possible, they also provide the technological means to produce and disseminate a highly timely ICD.

While the changes I have identified focus on mortality, but they are applicable to many other nonstatistical applications of ICD. I believe that the future offers great opportunities and challenges to WHO, to the Collaborating Centres, and to specialists who use ICD in their respective countries to produce statistical data, to render health care, and to administer health systems. WHO and the Collaborating Centers can play a leadership role in harnessing these changes to produce higher quality, more timely, and more comparable international health data.

APPENDIX: SUMMARY OF RECOMMENDATIONS

Mortality Reference Group[c]

- MRG should clarify the concept of underlying cause of death by distinguishing between reported underlying cause of death, originating antecedent condition, and tabulated underlying cause of death.
- WHO should redouble efforts to promote use of the international death certificate and the international coding rules for mortality.
- Even if there were no official ICD updating process, WHO should support the MRG as the official international body of experts who can—in their deliberate, systematic, and informed manner—resolve important mortality coding questions. Further, because of the increasing ICD emphasis on nonstatistical applications of ICD, the MRG provides a critical presence, both substantively and symbolically, of those who use ICD for statistical and research purposes rather than for health and medical administration and medical billing and reimbursement.
- MRG and the Electronic Tools Committee should monitor developments in electronic death registration, such as who certifies cause of death and the use of lists to select cause of death, to ensure that inappropriate practices and technology do not result in poorer quality cause-of-death information.
- WHO should make concerted efforts to incorporate updates into ICD and to rapidly disseminate the updated ICD. If this is not feasible, WHO should explore alternatives such as delegating certain dissemination responsibilities to Collaborating Centers.

Future of Automating Mortality Statistics

- Initiatives need to be undertaken to develop front-end systems for use with computer programs like ACME and TRANSAX that automatically select the underlying cause of death and that produce multiple cause data. Front end systems like SuperMICAR not only reduce the cost and effort of data entry, but they also can yield highly detailed diagnostic information. WHO should support and encourage such efforts, since they will facilitate the wider adoption of automated systems that result in more comparable international mortality statistics.
- Studies should be undertaken to assess the impact of automation on mortality statistics, including the effect of using electronic death registration.

The U.S. Experience in Implementing ICD–10 for Mortality

- WHO, in contemplating future revisions, should consider the impact of major revisions on individual countries in terms of their costs of implementation and the impact of implementation on ongoing national statistical operations.
- WHO should involve a mix of specialists in implementation and updating including medical classification specialists, statisticians, programmers and systems analysts, and physician/epidemiologists.

Training

- ICD training packages have to be continuously updated. Trainers in ICD for vital statistics are best taken from those directly involved in national vital statistics operations, production, and data analysis.
- WHO can play an important role by brokering bilateral technical assistance and training arrangements, and by using the Subgroup on Training and Credentialing to identify training resources.

International Technical Assistance

- Of paramount concern in many countries is the quality of cause-of-death reporting and the need for physician training in medical certification of death. Training physicians on how to complete death certificates needs to be tailored to the environments of different countries and to the way in which physicians in the respective countries are educated, and subsequently enter internships and residencies. Opportunities also exist for training physicians later in their medical careers through Continuing Medical Education programs in the U.S., or their equivalents in other countries. In addition, Internet-based resources are also available, including interactive tutorials. One such site is the mortality homepage of the U.S. National Center for Health Statistics at: http://www.cdc.gov/nchs/about/major/dvs/handbk.htm

WHO can play a valuable role by making member nations aware of existing resources to train physicians on how to complete the medical certification of cause of death.

- WHO should assess data quality, and encourage countries with data of poor quality to seek technical assistance, and should broker bilateral technical assistance and training. Bilateral arrangements have a number of distinct advantages.
- WHO should encourage key stakeholders from different government sectors at the national level to recognize their mutual interest in good data.
- At the international level WHO and the UN should actively cooperate in promoting better quality data through development of cooperative strategies and supporting materials.
- WHO and the UN should consider encouraging formation of an interest group that promotes the development of national vital registration systems.

FIGURE 1. INTERNATIONAL FORM OF MEDICAL CERTIFICATE OF CAUSE OF DEATH

Cause of death		Approximate Interval between onset and death
I		
Disease or condition directly Leading to death*	(a).....	.....
	Due to (or as a consequence of)	
Antecedent causes	(b)	.....
Morbid conditions, if any, Giving rise to the above cause, Stating the underlying condition last	Due to (or as a consequence of)	
	(c)	.....
	Due to (or as a consequence of)	
	(d).....	.....
II		
Other significant conditions contributing to the death, but not related to the disease or condition causing it	.....	
	.....	

**This does not mean the mode of dying, e.g.heart failure, respiratory failure. It means the disease, injury, or complication that caused death.*

Source: World Health Organization, ICD-10, Vol. 2.

[1] Presented as an invited address at the annual meeting of the Heads of WHO Collaborating Centres for the Classification of Diseases, Brisbane, Australia, October 2002. This is to acknowledge Dr. Iwao Moriyama for inspiration and insights into ICD and mortality statistics.
[2] World Health Organization, International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Volume 2, Instruction Manual. Geneva, World Health Organization, 1993.
[3] Ibid.
[4] See the NCHS Web site as follows: http://www.cdc.gov/nchs/about/otheract/icd9/abticd9.htm
[5] See the NCHS Web site as follows: http://www.cdc.gov/nchs/about/otheract/icd9/abticd10.htm
[6] National Center for Health Statistics (NCHS), Proceedings of the International Collaborative Effort on Automating Mortality Statistics, Volume I. Kimberley Peters, editor. Hyattsville, Maryland, July 1999.
[7] National Center for Health Statistics, Proceedings of the International Collaborative Effort on Automating Mortality Statistics, Volume II. Arialdi Minino and Harry M. Rosenberg, editors. Hyattsville, MD, September 2001.
[8] WHO, op.cit., 1993.
[9] Ibid.
[10] Ibid.

[11] Ibid.
[12] Green, Delray, ''Preliminary findings on study of the rules for underlying cause,'' World Health Organization ICD/C/82.16. Caracus, Venezuela. December 7–14, 1982.
[13] Rosenberg, Harry M., ''Improving Cause-of-Death Statistics,'' American Journal of Public Health, Vol. 79, No. 5, May 1989, pp. 563–564.
[14] World Health Organization, The World Health Report 2000: Health Systems: Improving Performance, Geneva, Switzerland, 2000.
[15] Roberts, Rosemary; Kerry Innes, Sue Walker, Michelle Bramley, Harry Rosenberg, ''Updating ICD–10. WHO/GPE/CAS/C/01.32. Bethesda, Maryland. October 21–27, 2001.
[16] NCHS, op. cit., 1999 and 2001.
[17] NCHS, op.cit., 2001.
[18] Ibid.
[19] Ibid.
[20] Ibid.
[21] Coleman, Michel P. and Paul Aylin, Death certification and mortality statistics: An international perspective, Studies on Medical and Population Subjects No. 64. London: Office of National Statistics, 2000.
[22] Rosenberg, Harry M., ''Cause of Death as a Contemporary Problem,''J Hist Med Allied Sci, Vol. 54, pp. 133–153. April 1999.
[23] WHO, op.cit.,1993.